THE EFFECT OF AN INFORMAL CAREGIVER'S PROGRAMME ON THE CARE OF PATIENTS INFECTED WITH HIV/AIDS

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of the requirements for the degree of
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DECLARATION

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Background & rationale: South Africa is faced with the major challenge of HIV/AIDS. Every South African has a vital role to play in managing this public health problem. One of the best ways of managing it is by informing and educating the communities about HIV/AIDS, as the communities lack knowledge about it.

Problem statement: Due to the increase in the number of patients infected with HIV/AIDS, an informal caregiver's programme was introduced to ensure that patients are better cared for at home, in a familiar environment and by their family members.

Purpose and objectives: The purpose of the study was to evaluate the effect of an informal caregiver's programme on the care of patients with HIV/AIDS. The objectives included evaluating the effect of care, physically, socially, spiritually, emotionally, information and educational support given.

Methodology: A phenomenological research design was applied to evaluate the effects of an informal caregiver's programme implemented for the care of patients infected with HIV/AIDS at Mfuleni Township in the Cape Metropolitan area.

Population and sampling: The population of this study were HIV/AIDS infected patients who were participating in the informal caregiver's programme. Ten of these patients, who gave consent, participated in the study.

Reliability, validity & pilot study: The trustworthiness of this study was assured with the use of Lincoln and Guba criteria of credibility, transferability, dependability and conformability. A pre-test study was also completed.

Ethical considerations: Ethical approval was obtained from the Stellenbosch University and the required consent from the individual participants.

Data collection, analysis and results: Data was collected through an interview using an interview schedule based on the objectives. Data was analysed and the

findings show that the care given to patients infected by HIV/AIDS at home through an informal caregiver's programme has a positive outcome.

Recommendations and conclusion: On the spot training of participants and their family members is recommended. The community health workers form a very strong support base for the participants.

OPSOMMING

Agtergrond en rasionaal: Suid-Afrika kom te staan voor ’n reuse uitdaging t.o.v. HIV/VIGS. Elke Suid-Afrikaner het ’n belangrike rol te speel in die beheer van hierdie openbare gesondheidsprobleem. Een van die beste maniere om dit te beheer, is om gemeenskappe in te lig en op te voed aangaande MIV/VIGS, aangesien daar ’n gebrek aan kennis hieromtrent is.

Probleemstelling: Weens die toename in die aantal pasiënte wat deur MIV/VIGS geaffekteer word, is ’n informele versorgingsprogram daarop ingestel om te verseker dat pasiënte beter tuis versorg word in ’n bekende omgewing en deur hul familielede.

Doel en doelwitte: Die doel van hierdie studie was om die effek van ’n informele versorgingsprogram in die versorging van pasiënte met MIV/VIGS te evalueer. Die doelwitte is uiteengesit om die effek van die versorging wat gegee is, te evalueer met verwysing na die fisiese, sosiale, geestelike, emosionele, inligting en opvoedingsondersteuning te evalueer.

Metodologie: ’n Fenomenologiese navorsingsontwerp is toegepas om die effekte te evalueer van ’n informele versorgingsprogram wat geïmplementeer is vir die versorging van pasiënte wat deur MIV/VIGS geaffekteer is in die Mfuleni woonbuurt in die Kaapse Metropolitaanse area te evalueer.

Bevolking en steekproef: Die bevolking van hierdie studie is MIV/VIGS geaffekteerde pasiënte wat deelgeneem het aan die informele versorger se program. Tien van hierdie pasiënte wat toestemming verleen het, het deelgeneem aan hierdie studie.

Betroubaarhied, geldigheid en loodsondersoek: Die betroubaarheid van hierdie studie is verseker deur die gebruik van Lincoln en Guba se kriteria van geloofwaardigheid, oordraagbaarheid, afhanklikheid en ooreenstemmigheid. ’n Aanvoortoets is ook voltooi.

Etiese oorwegings: Etiese goedkeuring is van die Stellenbosch Universiteit en die vereiste toestemming van die individuele deelnemers verkry.

Dataversameling, analise en uitslae: Data is ingesamel deur gebruik te maak van ’n onderhoudskedule wat gebaseer is op die doewitte. Data is geanaliseer en die bevindinge het bewys dat versorging wat by die huis deur ’n informele versorgingsprogram aan pasiënte gegee word wat met MIV/VIGS geaffekteer is, ’n positiewe uitkoms het.

Aanbevelings en gevolgtrekkings: Op-die-plekopleiding van HIV geïnfekteerde pasiente en hul familielede word aanbeveel. Die gemeenskap se gesondheidswerkers bied ’n sterk ondersteuningsbasis aan die deelnemers.

ACKNOWLEDGEMENTS

To the ONE who is above all, who made this a success – our Heavenly Father.

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- Congregants of Antioch Ministry – thank you for your prayers and God Bless.

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARK	Absolute Return for Kids
ARV	Anti-Retroviral
CBHPs	Community Based Health Programs
CBO	Community Based Organizations
CHW	Community Health Worker
DOTS	Directly-Observed Treatment Support
HIV	Human Immunodeficiency Virus
NDoH	National Department of Health
NGOs	Non-Governmental Organizations
PHC	Primary Health Care
TB	Tuberculosis
VCT	Voluntary Counselling and Testing

LIST OF DEFINITIONS

The following terminology utilized in the study is defined or clarified to ensure consistent interpretations.

AIDS:

Acquired Immune Deficiency Syndrome – AIDS is a unique disease, caused by the most primitive of all in the microbiological world, a virus called the Human Immunodeficiency Virus (HIV) which is a devastating disease and is currently the fourth largest killer worldwide (Worawan, 2003:55-71).

Epidemic:

An outbreak of disease, which spreads rapidly through a community (Granich, 2006:237-238).

Family Caregiver:

Is an individual who is related to a person with AIDS either genetically or through marriage or as a lover, significant other, friend, or someone who performed surrogate family functions (Worawan, 2003:55-71).

Health:

Being well or healthy in your body, mind and spirit and living in a healthy family, community and environment (Clarke, 2003:3).

HIV:

Human immunodeficiency virus: ‘human’ because the virus causes disease only in people; ‘immunodeficiency’ because the immune system which normally protects the person from disease becomes weak; ‘virus’ because like all viruses HIV infects living things and uses them to make copies of itself (Granich, 2006:237-238).

Informal Caregivers:

Providers of health services in the home in order to promote, restore and maintain a person’s maximum level of comfort, function and health, including care towards dignified death (Campbell, 2004:5-14).

Informal Caregivers Programme:

Is any programme performed by CHWs at community level in advocating for and accessing health services and assisting the community to become better informed about health priorities (Dick, 2008:680-681).

Lay Workers:

They are informal caregivers who also form a part of the comprehensive caring including anti-retroviral access (National Department of Health (NDOH), 2003).

Palliative Care:

Comprehensive care of people with active, progressive, far advanced disease that the prognosis is limited and the focus of care is the quality of life (Uys, 2003:8).

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CHAPTER 1

SCIENTIFIC FOUNDATION OF THE STUDY

1.1 INTRODUCTION

South Africa is faced with the major challenge of human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). Every South African has a vital role to play in managing this public health problem and one of the best ways of managing it is by informing and educating the communities about HIV/AIDS, as indicated in the National Strategy 2007-2011. According to the national and provincial indicators for 2006 people diagnosed with HIV in South Africa was about 5.4 million (Dorrington, Johnson, Bradshaw and Daniel, 2006:2). However, this figure has now increased to 5.7 million, a prevalence rate of a little over 11%, out of a population of nearly 48 million, of which about 600 000 are sick with AIDS (UNAIDS, 2008). Due to the increase in the number of patients infected with HIV/AIDS, an informal caregiver's programme was introduced to ensure that patients are better cared for at home, in a familiar environment and by their family members. Studies of previous researchers have shown that caring for the patient infected with HIV/AIDS at home with the support of an informal caregiver's programme has a positive outcome on the care of these patients. Through this study the researcher intends to evaluate the effect of the informal caregivers programme in the Mfuleni area.

1.2 RATIONALE

Based on the National and Provincial indicators for 2006 the demographic impact of HIV/AIDS in South Africa, shows that the Western Cape has the lowest HIV/AIDS rate namely, 267289 while Kwa-Zulu Natal has the highest HIV/AIDS rate of 1540183 as shown in table 1.1. The age group mostly affected is between 20-34 years of age, with the highest incidence among the females as shown in figure 1.1 (Dorrington, Johnson, Bradshaw and Daniel, 2006:1-25).

Table 1.1: The demographic impact of HIV/AIDS in South Africa. National and provincial indicators for 2006 (Dorrington, Johnson, Bradshaw and Daniel, 2006:1-25).

People living with HIV/AIDS	Kwa-Zulu Natal	Western Cape	South Africa
Total HIV infections	1 540 183	267 289	5 372 476
Adults (20-64)	1 376 555	250 796	4 880 464
Adult men (20-64)	617 185	97 005	2 178 752
Adult women (15-49)	759 370	153 792	2 701 712
Adults aged (15-49)	1 346 457	243 337	4 755 813
Men aged (15-49)	550 308	89 081	1 946 132
Women aged (15-49)	796 148	154 256	2 809 681
Youth (15-24)	324 996	36 300	1 012 167
Male Youth (15-24)	62 833	36 300	180 445
Female Youth (15-24)	262 163	5 510	180 445
Children (0-14)	97 088	11 453	293 549

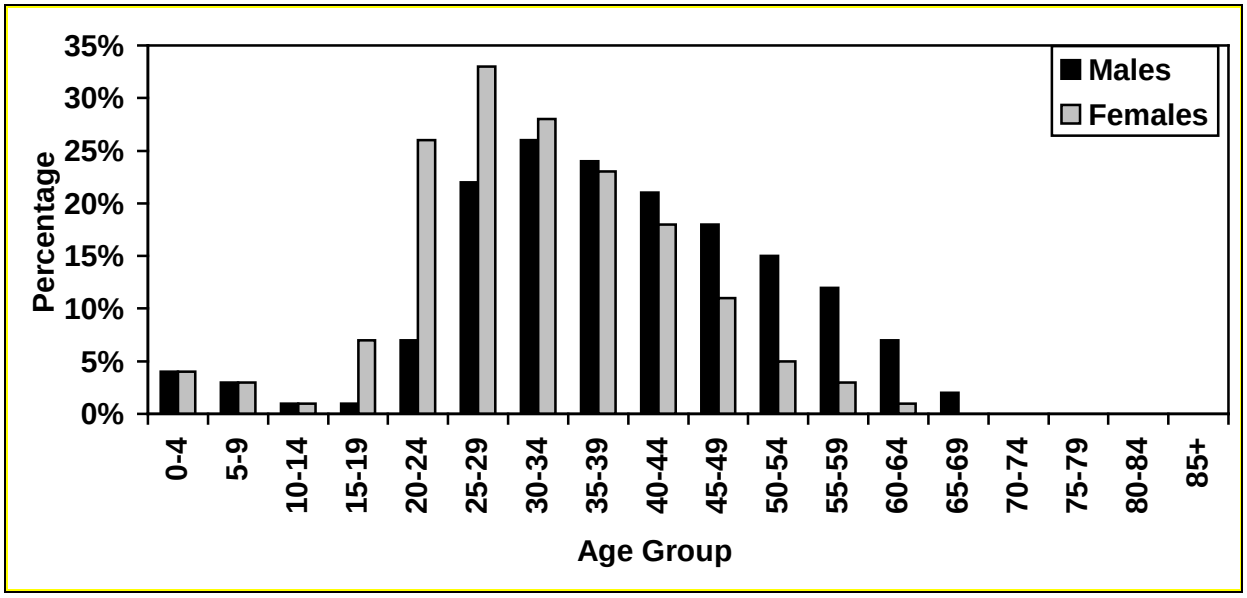

Figure1.1: Estimated prevalence of HIV by sex and age, 2006 (Dorrington, Johnson, Bradshaw and Daniel, 2006:1-25).

In the Mfuleni area of the Western Cape a large influx of people has been experienced since 2008, which has now impacted negatively on an already exhausted and overcrowded health service. The increase in patient load has also influenced the rate of HIV/AIDS becoming more and more alarming. HIV and AIDS projections at Mfuleni area, the area where the intended research is to be

conducted include two clinics: Mfuleni Community Health Centre (CHC) and Dr. Ivan Tom's Clinic. Current population statistics show that there is an estimated 125 000 people living on the western side of the Eastern Sub-district, with about half (62 000) living in Mfuleni. In 2007, 2620 HIV tests were done at the Mfuleni CHC and Dr Ivan Tom's Clinic, including voluntary counselling and testing (VCT) of which 577 (24%) of the patients tested positive. Based on this result an analysis shows that an estimated one third of the patients (192) testing positive required anti-retroviral drugs (ARVs), which calculated to 16 patients to be initiated with a treatment regime each month (Mfuleni Audit, 2008). At the end of January 2008, 601 patients were on ARVs at Eersteriver Hospital. Approximately 50% of these patients are from Mfuleni. In addition, an estimated 200 Tygerberg Hospital (TBH) patients stabilised on treatment (50% adults and 50% children) were transferred from TBH to Mfuleni.

Despite the increase in the number of HIV/AIDS patients and patients being treated with ARVs, the number of informal caregivers is the same as at the beginning of 2008. Patients ill with HIV/AIDS are being cared for at home and additional support is given to each patient at least once a week and if fortunate twice a week for a maximum time period of 30 minutes. Patients are not seen over weekends. Due to the increasing rate of HIV/AIDS, informal caregivers' programmes have been introduced worldwide. Many of these informal caregivers' programmes have shown positive results as family caregivers in particular together with HIV/AIDS infected persons have gained more insight about HIV/AIDS and how to take care of their sick family members at home. Initially in South Africa the emphasis was placed on the primary health care system staffed with doctors and nurses. However, official support for CHWs has grown recently (Clarke, Dick and Lewin, 2008:680).

Various observations about patients infected with HIV/AIDS and affected by the disease have been made namely socially, physically, emotionally and spiritually. Observations in the clinical environment include:

- Inadequate number of staff members to manage these patients due to human resource constraints.
- Limited number of hospital beds, as a result of overflow of patients that are infected with HIV/AIDS.

- Lack of information and education by the communities with regard to HIV/AIDS resulting in stigmatisation.
- Unhealthy or risky lifestyles further aggravated the prevalence of HIV/AIDS.
- Traditional or cultural influences increased the risk of HIV/AIDS.
- Lack of a support base for HIV/AIDS infected persons.

Furthermore in her clinical practice the researcher observed that the loneliness of the HIV/AIDS infected patient is because of discrimination, social stigma, judgement, rejection, support deficiencies and unmet support needs. As soon as HIV/AIDS infected patients are aware of their status they immediately become concerned about the cost of the treatment and survival needs which include housing, child care, transportation, legal services and loss of employment. A further observation included couples blaming each other, creating conflict within the family. Role change takes place, during which either the father or the mother can no longer perform their normal daily tasks. It was observed that many mothers become the bread winners in their families.

In addition many complications are associated with the HIV/AIDS infected patient. It is confirmed that malnutrition and weight loss are as a result of the increased risk of opportunistic infections as well as the side-effects of antiretroviral treatment. This is confirmed by Visser (2005:464-469) as described in figure 1.2 on page 5.

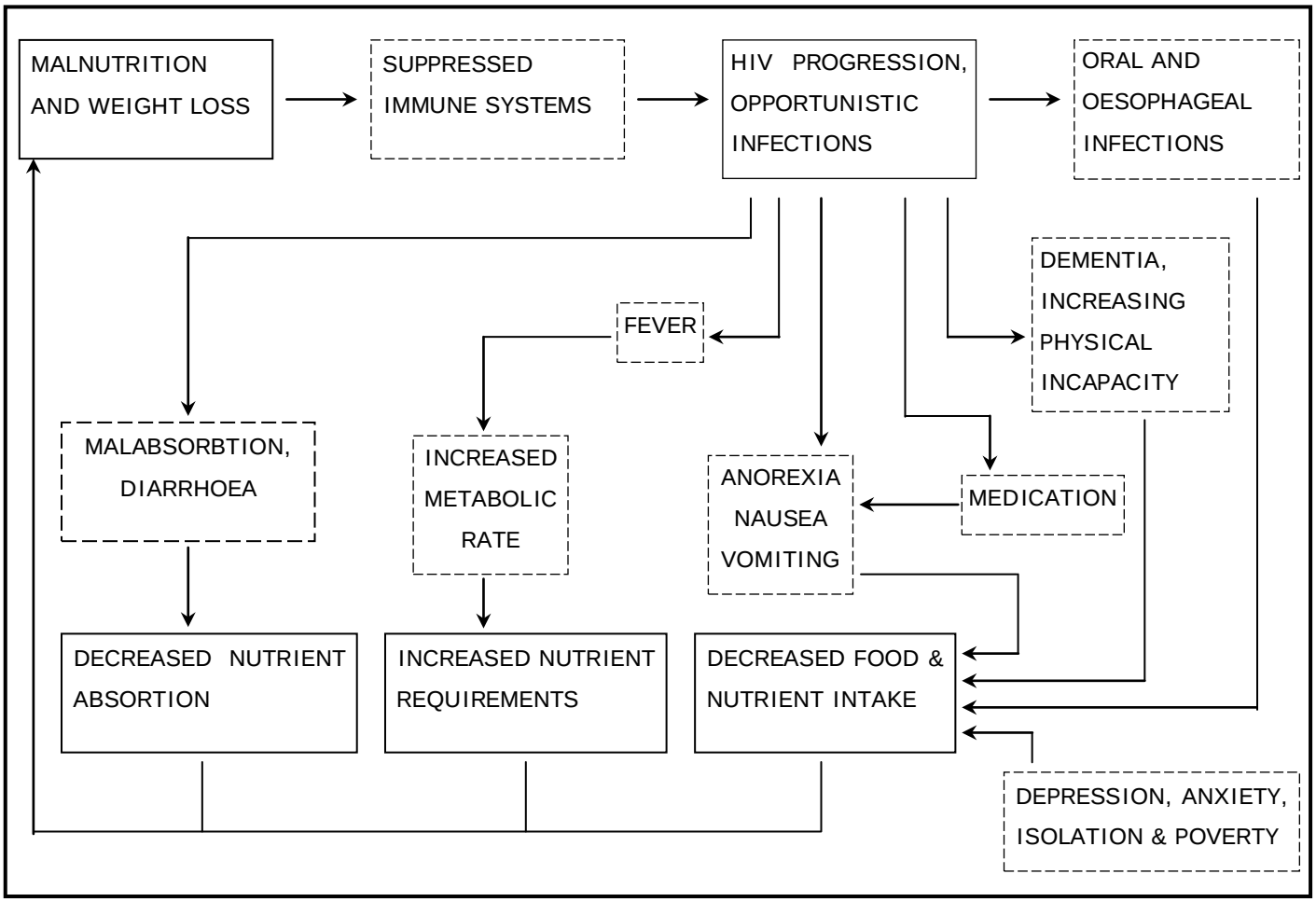

Figure1.2: Malnutrition and risk of opportunistic infections (Visser, 2005:464-469).

According to Karim (2005:454-456), nearly all opportunistic infections are caused by infectious agents or malignancies associated with viruses. Exposure to opportunistic infections should be prevented wherever possible by paying attention to safe water supplies, food hygiene, tuberculosis (TB) prevention and practicing safe sex. Chemoprophylaxis has an important prevention role in late infections. Many opportunistic infections associated with HIV infection are preventable, as shown in table 1.2 on page 6.

COMMON ↑	TUBERCULOSIS
	OESOPHAGEAL CANDIDIASIS
	BACTERIAL PNEUMONIA
	CHRONIC HERPES SIMPLEX ULCERS
	DIARRHOEA (CRYPTOSPORIDIOSIS / MICROSPORIDIOSIS /
	ISOSPORIASIS)
	PNEUMOCYSTIS CARINII PNEUMONIA
	BACTERAEMIA
	MALARIA
	CRYPTOCOCIOSIS
	TOXOPLASMOSIS
	CYTOMEGALOVIRUS
RARE	DISSEMINATED NON-TUBERCULOSIS MYCOBACTERIUM
	DISSEMINATED ENDEMIC MYCOSIS

Table 1.2: Potentially preventable opportunistic infections approximately ranked from rare to common (Karim, 2005:454-456).

According to Treisman (2004:195-208) symptoms of depression are the most common psychiatric complication of a chronic illness. Depression is a significant problem in HIV/AIDS, as it is a risk for perpetuating the epidemic and preventing the effective treatment of infected individuals. Persons with depression are careless about their own safety, feel hopeless and are more impulsive.

Alcoholism, substance abuse disorders and high-risk sexual behaviour aggravate the incidence of HIV/AIDS across a wide range of settings as identified with crack-cocaine abusers who are likely to engage in prostitution to obtain the money needed to buy the drugs (Hsu, 2004:101-152).

Therefore, the search for a cost-effective alternative management of these patients has become imperative to minimize the problems associated with the HIV/AIDS epidemic. The Absolute Return for Kids (ARK) programme in South Africa (2002), introduced an informal caregiver's programme, whereby home-based carers as well as patient advocates have a general care-plan as well as assessment

guidelines that attends to problems such as personal hygiene, prevention of infection, pressure care, catheter care, wound care, dehydration, nutrition, constipation, supervision and administering of treatment. This programme has shown positive results as some of the family caregivers verbalized some insight as to how to take care of HIV/AIDS infected patients. Weekly assessment and home visits are done by patient advocates as well as home-based carers to ensure that the required care is given.

The Directorate of Nutrition in the Department of Health (2005) compiled a handout emphasising "Eating well while coping with the symptoms of illness" which describes physical problems such as managing heartburn, bloating, diarrhoea, constipation, vomiting, fever, sore mouth and throat, oral hygiene and swallowing problems. Furthermore, these handouts are being given to HIV/AIDS infected persons and their family caregivers during voluntary counselling and testing (VCT) at different health institutions such as at Dr. Tom's Clinic.

In response to the growing demands of the HIV epidemic, Becky, Johnson and Khanna (2004:496-502) introduced community Health Workers and Home-based Care Programmes for HIV clients in Nyanza Province, a rural area in Kenya. This programme specifically targets the majority of individuals who do not have access to medical facilities on a regular basis. The programme has trained hundreds of lay individuals as community health workers which provide home-based care to sick or dying HIV/AIDS clients in rural areas. The health workers also played a role in providing HIV/AIDS education to individuals in an attempt to prevent further infections.

According to Richter and Peu (2004:31-40) the educational and supportive needs of informal caregivers should be explored and described. These will assist in planning and establishing health education programmes and a supportive network including workshops, HIV/AIDS counselling, communication skills, use of community advisors such as priests who support the spiritual needs of the patient.

Stewart, Hart, Tackson, Langille and Reidy (2001:209-225) introduced a pilot project to test the feasibility of a telephone support group. This support group

comprised of six people who included a professional and five persons infected with HIV/AIDS. The focus of this 12 week pilot study was to share personal experiences with family caregivers and patients infected with HIV/AIDS. The intervention has shown the following results:

- All participants reported that the telephone groups had a positive impact on meeting their support needs.
- They believed that they benefited from sharing information.
- The support groups had decreased their feelings of isolation and loneliness.
- Participants indicated that the intervention should be longer than 12 weeks.

Campbell (2004:5-7) looked at people's lifestyles and believed that if local people participated in community-based public health projects designed to promote health-enhancing behaviours, such participation influenced health behaviours in a range of ways. Firstly, people with sexually transmitted infections (STi's) are more likely to perform healthy behaviours such as accessing of health services. In addition the individual's sense of perceived self-efficiency or empowerment includes taking control of their health.

Shaibu (2006:89-94) developed an outreach program based on how to render culturally sensitive care and strategies for dealing with these challenges. For example some patients at some point may abandon Western biomedicine such as the antiretroviral treatment for traditional or other alternative healing methods. Cultural patterning strategies can be used to meet and negotiate with traditional healers regarding treatment. This could be illustrated where a traditional healer would need to administer an enema to a dehydrated patient who already has diarrhoea or vomiting, the traditional healer can be persuaded to postpone it until a later date when the patient is in a condition to sustain such treatment.

On the 19th May 2009 in a live television broadcast discussion, Morning Live on SABC 2, the introduction of community based programmes were substantiated further. An ex-lay counsellor Rose Thamae started an informal caregiver's programme in 1990 called "Let us grow" project in Orange Farm Ward 1. This programme was started with five women who acted as a support group and as community health workers. The programme has now increased to 75 support

persons with 1600 HIV/AIDS infected people receiving anti-retroviral treatment (ARVs). The role of the community workers / support persons included teaching persons infected with HIV/AIDS and affected family and friends about acceptance, disclosure about their status and how to live positively. Furthermore due to poverty and a lack of nutrition a soup kitchen was introduced.

Against this background the significance and value of a caregiver's programme received more impetus in the workplace. As part of a multi-disciplinary approach, an informal caregiver's programme for the care of patients infected with HIV (See addendum D), based on the following was introduced:

- Information for families or carers about the care for the patient with HIV/AIDS, as described by Becky (2004:496-502).
- Skills training in managing the basic needs of the HIV/AIDS patient such as hygiene, nutrition and positioning.
- Information about when to seek medical assistance, if the need may arise.

1.3 PROBLEM STATEMENT

In the light of the above discussion the researcher has shown that it was essential to introduce an informal caregiver's programme due to the growing number of patients affected and infected by HIV/AIDS. The programme emphasised special training for caregivers, distribution of handouts and periodic visits to family homes. The training of informal caregivers was further enhanced by on the spot teaching in the home environment of the patient rendering an individualised approach. It has therefore become essential to evaluate scientifically the effect of the existing informal caregiver's programme which was introduced for patients attending the Mfuleni Clinic in 2008.

1.4. RESEARCH QUESTION

The researcher posed the following research question as a guide for this study:
"What was the effect of an informal caregiver's programme on the care of patients infected with HIV/AIDS?"

1.5 PURPOSE OF THE STUDY

The purpose of this study was to evaluate the effect of an informal caregiver's programme on the care of patients infected with HIV/AIDS.

1.6 RESEARCH OBJECTIVES

The following objectives were set to evaluate the effect of the care given with reference to:

1.6.1 emotional care
1.6.2 spiritual care
1.6.3 social care
1.6.4 physical care
1.6.5 informational and educational support

1.7 RESEARCH METHODOLOGY

A brief description of the research methodology implemented in this study is given, while a more in-depth description is described in chapter 3.

1.7.1 RESEARCH DESIGN

A phenomenological descriptive research design with a qualitative approach was applied to evaluate the effect of an informal caregiver's programme implemented for the care of patients infected with HIV/AIDS at Mfuleni Township of the Cape Metropolitan Area. The effect of the programme was determined by exploring the patients' experience about the care given to them. According to Burns and Grove (2009:696) a research design is the blueprint for conducting a study, it maximizes control over factors that could interfere with the validity of the findings, guides the planning and implementation of a study in a way that is most likely to achieve the intended goal. However the phenomenological design allows the researcher to understand and interpret the meaning that the participants give to their everyday lives (de Vos et al. 2005:270).

1.7.2 POPULATION and SAMPLING

For the purpose of this study, patients who were being cared for by caregivers, and who participated in the informal caregiver's programme were eligible to participate in the study. At the time of the research fifteen (15) patients were participating in the programme and were receiving care for a period between 3-12 months.

According to De Vos et al. (2005:192-204), a maximum of ten (10) participants can be included in the sample, and data collection could occur until saturation point is reached. For the purpose of this study ten (10) patients were interviewed. A simple random sample was applied to draw ten (10) names from a group of fifteen (15). All the names were placed into a hat and the first ten (10) names drawn formed the sample.

1.7.3 MEASURES TO ENSURE TRUSTWORTHINESS

The application of the principles of trustworthiness as described by Lincoln and Guba (1985:29): credibility, transferability, dependability or conformability were applied in this study.

1.7.3.1 Credibility

According to De Vos, Strydom, Fouché and Delport (2005:346), credibility is the "…alternative for internal validity in which the goal is to demonstrate that the inquiry was conducted in such a manner as to ensure that the subject was accurately identified and described". For the purpose of this study the goal was to evaluate the effect of an informal caregiver's programme on the care of patients with HIV/AIDS. Only subjects who were participants in the programme introduced for the Mfuleni Comprehensive Clinic and Dr Ivan Tom's Clinic were included in this study and who were involved in the programme for a period of 3-12 months. In addition experts in the field of nursing and research methodology were consulted to determine the feasibility and content of the study, to evaluate the research process and outcome. Internal validity / truth-value or credibility was ensured by being

satisfied that the participants accurately understood the questions and agreed with the way it was interpreted.

1.7.3.2 Transferability

According to Lincoln and Guba (1985:19-22), this is the alternative to external validity, however as described by de Vos et al. generalizability is problematic in qualitative research. To counteract this problem the researcher formulated a theoretical foundation for the study based on the basic needs of patients or individuals. The conceptual theoretical framework for this study was based on the models and theories of Florence Nightingale who describes the therapeutic environment within which the patient must be nursed. Henderson, Abdellah and Maslow refer to the basic needs of patients. The principle of transferability as applied in this study will therefore ensure that the findings of this study may be applied to other HIV/AIDS patients who need to be cared for by informal caregivers. To ensure consistency similar findings will be obtained if the study is repeated with the same participants i.e. patients being cared for by caregivers.

1.7.3.3 Dependability

Dependability is referred to as the alternative to reliability although very different as the social world is constantly changing. For the purpose of this study the researcher ensured consistency / dependability by the meticulous recording and note taking during and after the interviews with participants and using the same technique in conducting each interview. The researcher used the same interview schedule and where necessary probed and added additional questions as the in-depth discussion progressed. Data was transcribed and analysed after every interview. The experiences of participants who participated in the research were accurately described or interpreted. For this purpose a tape recorder was used to ensure that all information as described by the participant was captured. Truth value and applicability were established consequently neutrality or conformability of data was achieved.

1.7.3.4 Conformability

A fieldworker or fieldworkers were trained to ensure that objectivity / neutrality / conformability were maintained due to the researcher's involvement in the programme. In addition a reflective diary was kept by the fieldworker with her reflexive thoughts, to ensure that the fieldworker remained neutral when probing into a participant's lived experiences. Furthermore, after transcribing each participant's data it was verified with the particular individual to ensure that the data was transcribed accurately and that bias was excluded.

1.7.4 INSTRUMENTATION

In qualitative research data collection is guided by an interview schedule or guidelines with main questions (De Vos et al., 2005:292-3). For the purpose of this study an interview schedule containing four core-questions was used to guide a semi-structured interview (See annexure A, page 81).

1.7.5 PRE-TEST OR PILOT STUDY

A pre-test of the study was conducted using one of the actual number of participants of the sample who was not included in the study. The purpose of a pre-test is to test the feasibility of the study and the guidelines being used (De Vos et al., 2005:292-3).

1.7.6 DATA COLLECTION

A trained fieldworker interviewed the patients individually. The interviews were recorded with the use of a tape recorder with permission from the interviewee. A guideline containing four core questions based on the objectives of the study was used to guide the interviews (See annexure A, page 81).

1.7.7 DATA ANALYSIS

The researcher analysed the data by listening to the tapes and transcribing the participant's recorded interviews. Data was explored in detail for common themes and these were then established into units of means or codes. According to Burns and Grove (2007:88), the emphasis is on identifying themes and patterns in the data. Coding could also be used to expand, transform and reconceptualise the data providing opportunities for more diverse analysis.

1.8. ETHICAL CONSIDERATIONS

Permission to conduct the study was obtained from the Ethical Committee, Faculty of Health Sciences, Stellenbosch University (See annexure B, page 82). Informed written consent (See annexure C, page 83) was obtained from individual participants, ensuring confidentiality. Informed written consent was obtained in Xhosa as all participants are Xhosa-speaking. The written consent was also evaluated by the Ethical Committee. Furthermore, the researcher and assistant facilitator are also Xhosa-speaking which facilitated communication between the participant and the fieldworker. Data was transcribed into English. All data obtained was managed by the researcher, fieldworker and supervisor only. In the final analysis it was not possible to link any specific data to a participant.

In addition, Section 5 of Regulation 387, Acts and Omissions as promulgated by the Nursing Act (No 50 of 1978) states that a nurse may not divulge any information concerning a client, which has become known to him/her in his/her professional capacity. However it is generally recognised that team management necessitates 'extended' confidentiality, which includes other members of the treatment team even if the client has not agreed to share such information. This regulation makes provision for nurses to share information with colleagues involved in the treatment of the same client, but is silent on sharing information with the significant others of the client.

According to Geyer (2001:48), the healthcare professional may not inform the sexual partner of the client's status unless:

- The sexual partner is clearly identifiable;
- There is a real risk that the partner is at risk of infection (if the health worker knows, there is a possibility that the partner may sue);
- The client has been counselled of the dangers involved if he or she does not inform their partner;
- The healthcare professional has requested the client to divulge the HIV status to the partner;
- The healthcare worker has warned the client that if he or she does not practise safer sex or inform the partner, that confidentiality would be broken and the partner informed.

Based on this protocol, there are occasions where the healthcare professional will have an obligation to inform the sexual partner of the patient. However, the accurate and complete records of all the procedures should always be maintained.

The Constitution of South Africa is clear about the right of the client to privacy. Section 14(d) states that everyone has the right to privacy, which includes the right not to have the privacy of their communications infringed. Data will be stored in a locked cupboard accessible to the researcher and supervisor as it is intellectual property of Stellenbosch University and will be destroyed 5 years after the completion of the study.

1.9 CONCLUSION

In this chapter, the rationale for the study was discussed, supported by the literature, the purpose and objectives. In addition the research methodology was described specifically directed at describing the research design, validity, instrumentation, data collection, analysis and ethical considerations.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

Over the last decade in South Africa, a rapid growth in programme activities and budgetary allocations for the comprehensive response to HIV/AIDS has resulted in an emergence of a large number of various community based programmes. It began in the mid-1990s with state support for non-governmental organizations (NGOs) employing home and community-based carers and the training of lay counsellors. The rationale for introducing these programmes was to promote voluntary HIV testing and for the directly-observed treatment support (DOTS) programme (Russel & Schneider, 2000:327-333). DOTS workers, being informal caregivers, who ensure that Tuberculosis (TB) patients take their treatments and test for HIV voluntarily. Lay workers, who are informal caregivers, also form part of the comprehensive care including anti-retroviral access (National Department of Health (NDoH), 2003).

According to Steyn, Van Rensburg and Engelbrecht (2006:113), lay workers are an indispensable extension of the strength of professional involvement in anti-retroviral treatment (ART) services. By 2004, there was an estimated 40 000 such lay workers in South Africa (NDoH 2004a), nearly equal to the number of professional nurses of 43 660 working in the public sector (Day & Gray, 2005:180-189). In 2005 the government introduced the umbrella term ‘Community Health Worker’ (CHW) for their training and remuneration (NDoH, 2004b; Friedman, 2005:176-188). The majority of CHWs in South Africa are the human immunodeficiency virus (HIV) and tuberculosis (TB) workers. Expansion and regulation of the CHW infrastructure now features in both the National Strategic Plan for HIV/AIDS (NDoH 2007:2011) and medium-term human resource plans for the health sector (NDoH 2006a).

2.2. COMMUNITY HEALTH WORKERS (CHW)

CHWs are members of the community in which they work, who serve and respond to the health needs of the community. In addition CHWs play a unique role as part of the health, welfare and development team (Cruse, 1997:1-40).
The official title 'Community Health Worker' is yet to become institutionalised in the health system. Terms such as lay and community workers, home-based carers, community caregivers and volunteers are still frequently used as generic descriptors of the category. This loose definition comes closest to capturing the wide range of CHW roles in South Africa, rather than the more normative and specific definitions proposed by WHO (1989) and in the CHW Framework (NDoH 2004b).

The first CHW initiatives developed in response to the need in poor communities for adequate health services not supplied by existing health services. At the same time there was a growing recognition of the importance of comprehensive health strategies that included preventative, promoting and rehabilitative measures as well as curative care. The 1978 Alma Ata conference, stressed the importance of primary health care (PHC) in bringing health to poor communities, underlined the key role of CHWs in achieving this goal through interventions which include the following:

i. Education on prevailing health problems and methods of prevention and containing the problem when identified;
ii. Promotion of food supply and good nutrition;
iii. An adequate supply of safe water and basic sanitation;
iv. Maternal and child health care, including family planning;
v. Immunisation against major infectious diseases;
vi. Prevention and control of locally endemic diseases;
vii. Appropriate treatment of common diseases and injuries;
viii. Provision of essential drugs; and
ix. Provision of basic curative care.

It was found that these activities were extremely challenging even for experienced health workers. Unrealistic expectations of what CHWs can be expected to achieve along these lines has caused disappointment in many programmes. Planners need to assist communities to determine priority areas for actions and see what is realistically possible with available resources. According to Matthews (1994:3), the issues to consider when assessing priorities include - prevalent morbidity and especially mortality, health issues of concern to the community and community amenability to intervention.

Community Health Workers have a task of:

- Identifying the community's health problems, causes and resources available to solve problems.
- Better health for all is what community health workers focus on through discussions, planning and actions taken by the community in order to take care of their health needs.
- Providing health information to families, individuals and communities through the organizing of special projects like the growing of vegetable gardens.
- Bringing health services to people in their own familiar environment; like their homes, visiting the sick, mentally disturbed, the disabled and older community citizens.
- Empowering communities through the sharing of information, knowledge, resources and skills (Clarke, 2003:3).

2.3. PALLIATIVE CARE

Palliative care is the term given to the approach adopted when cure is unlikely and it is expected that the patient will die in the foreseeable future. People of all ages die, in a range of settings – at home, hospitals, in nursing homes and in hospices. They die of many different diseases, some suddenly and some slowly (Runciman, Alexander, Josephine and Fawcet, 2003:1-1118). Palliative care has been developed to help those who are dying slowly or, as often said, living with dying. Led by the hospice pioneers, this approach to care has a recent and inspiring history (Dougan & Colquhoun, 2003:963-981).

Palliative care is comprehensive care of people with active, progressive, far advanced diseases of which the prognosis is limited and the focus of care is the quality of life (Uys, 2003:8). The goal of palliative care is the achievement of the best quality of life possible for patients and their families.

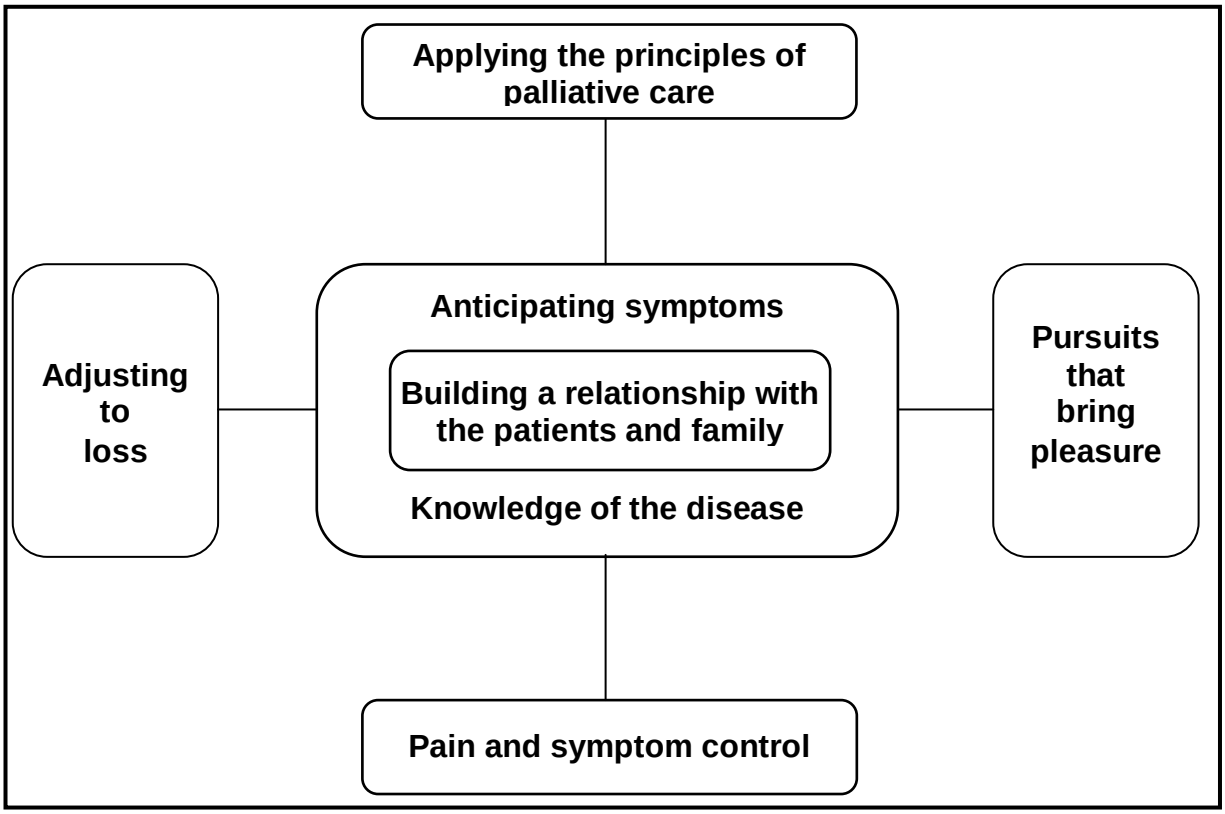

Figure 2.1: Model for palliative care (Runciman et al., 2003:1-1118)

The model as described in figure 2.1 by Runciman et al. (2003:1-1118), building a relationship with the patient and family members, to explore their experiences with the life-threatening illness and to become informed as to their functioning (i.e. their roles, bonds and coping strategies), as well as to ascertain their needs, priorities and wishes are essential. During the study the researcher tried building and maintaining a good researcher to patient/family relationship. By building such a relationship the HIV/AIDS patients and their families trusted the researcher enough to open up about their feelings and life experiences (Runciman et al., 2003:1-1118).

Anticipating symptoms – HIV/AIDS patients explain exactly how they feel physically and patients will be managed accordingly by community health workers and at the clinic. Information/education regarding management of patients' symptoms was given.

Applying the principles of palliative care:-

- Employ good control of symptoms, as explained above; symptoms are managed accordingly and education was given throughout.
- Facilitating adjustment to losses and pursuits that give pleasure (Runciman et al., 2003:1-1118).

Pain and symptoms control – an assessment of each symptom was made by asking exactly how the HIV/AIDS patient feels and then causes and treatment options are discussed. Planning of symptom management in the light of the HIV/AIDS patients' expectations and priorities was communicated by the CHW, nurses and doctors.

Facilitating adjustment – making adjustments from thinking of oneself as an ill person who is dying right now to thinking of oneself as a relatively healthy person who will die someday in the future is a very big step. It has been suggested that a useful starting point for understanding an individual's response to a life-threatening illness is to consider the question: "What does this illness mean to this person?" (Baraclough, 1999:1-50). It was important to explore the feelings of the HIV/AIDS patients and that of their family members during the study. Patients and families should be encouraged to talk to a priest, have family meetings and spend more time together privately.

Pursuits that give pleasure – play the piano if wished for and encourage visitors to accompany HIV/AIDS patient if the patient so wishes. More time with personal hygiene, to go to chapel, anything the HIV/AIDS patient wishes for, should be done as much as the patient wants (Baraclough, 1999:1-50).

The World Health Organization's description of palliative care places strong emphasis on the need for palliative care professionals to facilitate spiritual care (Sepulveda, 2002:91-96).

2.4. COMMUNITY BASED SUPPORT PROGRAMMES (CBSP)

Becky (2004:496-502) introduced community Health Workers and Home-based Care Programmes for HIV clients in Nyanza Province (rural area), Kenya. The majority of individuals do not have access to medical facilities on a regular basis. Between 1985 and 2002, over two million Kenyans became infected with the HIV virus. The HIV/AIDS epidemic in Kenya contends that cultural and socio-economic factors are the chief contributors to the high prevalence of this virus. Traditionally, the male is the sole breadwinner in the family and, depending on his economic status, may have two or more wives.

During a home-based care visit, the CHW may visit clients, assist in preparing meals, assist with household chores, give medication to treat opportunistic infections, or conduct a needs assessment to consider what supplies may be needed on the next visit. The CHW is also responsible for training the client's primary care-giver in safe and hygienic care-giving, opportunistic infection recognition, and appropriate medication administration. In addition to provide home-based care to those people who were suffering from HIV/AIDS and who were in the end stages of their lives, provide assistance, such as food, medical care and educational expenses to orphans (Becky, 2004:496-502; Uys, 2002:99-108).

Educational efforts have helped to shape a positive perception towards HIV-positive individuals. CHWs interviewed found their educational efforts in the community to be largely successful "because the community members are able to accept the teaching, and they become flexible and willing to be taught." The CHWs also counsel widows on the ramifications of wife inheritance (a traditional custom among the Luo and argued to be a contributing factor in the rapid transmission of the HIV virus in Nyanza Province). As one CHW suggested, the widows are listening (Becky, 2004:496-502).

Access to VCT services and community support services for those who test positive have shaped individuals' willingness to receive a test. According to one CHW: "now we are encouraging everybody to go for testing so that they know their status even if they are well." The number of openly HIV-positive clients in this program is indicative of the successes of the VCT program. Another CHW stressed the importance that anybody could be HIV-positive and that one of their roles as a CHW was to prove that point. She stated: "People normally want to know if the CHWs have been tested because when they provide counselling services, the assumption is that they have also been tested. I am an example to the community because I have already gone through counselling and have been tested."

Additionally, CHWs in Nyatike Division believe that the education they provide to the communities has helped to create a more-positive perception of people living with AIDS. As one CHW explained, "at first, people were afraid of the disease and those who were infected, but through education, through information and communication, through the program, then people have tried to know what it is and to see HIV and AIDS just as one of the diseases." (Becky, 2004:496-502).

Uys (2002:99-108) investigated home based care programmes by community health workers for people with HIV/AIDS as it became clear that hospital care was too expensive and that families found it difficult to cope on their own with the demanding care of people living with HIV/AIDS.

Community health workers felt positive about the contribution they made, but found it difficult to cope with the poverty and complexity of problems they were faced with. Community health workers visited each person with HIV/AIDS an average of five times per month and their care usually involved counselling and informing, symptom control, psychosocial support and welfare assistance. The community health worker works in close collaboration with the South African Hospice Association. In all of the visits the people living with HIV/AIDS and their families seemed positive about the visits and pointed out many improvements in the coalition of the people living with HIV/AIDS (Uys, 2002:99-108).

Support is needed to overcome the stigma associated with HIV/AIDS, to bolster self-esteem, to gain a sense of control and to reduce loneliness (Thomas, 2006:3174-3187). Support groups create provision of various types of support: informational, affirmation and emotional. These support groups enhances coping, communication and positive attitude. Simultaneously it reduces isolation and entails talking with others who understand (Friedman, 2002:177).

2.4.1. COMMUNITY PHYSICAL SUPPORT PROGRAMMES

Community physical support programmes are the programmes that focuses on how the physical aspects of people infected with HIV/AIDS become affected.

2.4.1.1. Maintenance of good hygiene and physical comfort

The Directorate of Nutrition in the Department of Health (2005) introduced an "Eating well while coping with the symptoms of illness" programme which describes how to manage various physical problems the infected patient may encounter such as heartburn, bloating, diarrhoea, constipation, vomiting, fever, sore mouth and throat, oral hygiene and swallowing problems. Furthermore, handouts are given to HIV/AIDS infected persons and their family caregivers for voluntary counselling and testing (VCT) at different health institutions such as at Dr. Tom's Clinic.

2.4.1.2. Supply of fluid and electrolyte balance

Shaibu (2006:89-94) developed an outreach program based on how to render culturally sensitive care and strategies for dealing with these challenges. For example some patients at some point may abandon Western biomedicine such as the antiretroviral treatment for traditional or other alternative healing methods. Cultural patterning strategies can be used to meet and negotiate with traditional healers regarding treatment. Shaibu further illustrated that where a traditional healer would need to administer an enema to a dehydrated patient who already has diarrhoea or vomiting, the traditional healer can be persuaded to postpone it until a later date when the patient is in a condition to sustain such treatment. Shaibu managed to create a link between the traditional healers and the health

professionals who took part in his study to reach an agreement on when to send a patient to a clinic and when to give traditional medicine.

2.4.1.3. Physiological responses of the body to disease conditions

As observed by Prachakul (2003:55-71), people with HIV/AIDS, due to advanced anti-retroviral treatments live longer and experience various physical impairments during the course of their illness. Often, informal caregivers assist people with HIV/AIDS to manage these impairments and experience negative physical and psychosocial consequences from their role. These physical impairments include wasting, severe muscular skeletal pain, neuropathies and blindness.

2.4.1.4. Nutrition, elimination, rest and sleep, safety needs, creating and maintaining of a therapeutic environment

Although not described scientifically, the Absolute Return for Kids (ARK) programme in South Africa (2002), have introduced an informal caregiver's programme, whereby home-based carers as well as patient advocates have a general care-plan as well as assessment guidelines that attends to problems like personal hygiene, prevention of infection, pressure care, catheter care, wound care, dehydration, nutrition, constipation, supervision and administering treatment. This programme has shown positive results as some of the family caregivers show and verbalizes some insight as to how to take care of HIV/AIDS infected patients. Weekly assessment and home visits are done by patient advocates as well as home-based carers to ensure that the required care is given.

2.4.2. COMMUNITY EMOTIONAL SUPPORT PROGRAMMES

Emotional support entails being sensitive, understanding, providing a conducive environment for the patients to be able to communicate their anxieties and fears, deriving comfort by being gentle and sympathetic to patients and increasing the ability of patients to take better care of themselves.

Whetten (2008:531) looked at the emotional factors as they relate to HIV/AIDS in the United States and globally. Whetten specifically focussed on mental illness including depression, anxiety and post-traumatic stress disorder. These factors have been found to be prevalent among individuals with HIV/AIDS, regardless of gender, race or ethnicity. Whetten further identified that these emotional factors are related to unemployment or disability, having more HIV-related symptoms and drug use.

Stewart, Hart, Tackson, Langille and Reidy (2001:209-225) introduced a telephone support group intervention for persons with HIV/AIDS and family caregivers. A pilot project to test the feasibility of telephone support was done over a period of 12 weeks. The composition of the support group included a support group for family caregivers that involved six people, co-led by a professional and five people infected with HIV/AIDS. The aim of including the infected individuals was to share personal experiences. The results show that all participants reported that the telephone groups had a positive impact on meeting their support needs. They believed that they benefited from sharing information and that the support groups had decreased their feelings of isolation and loneliness. Participants also indicated that the intervention should be longer than 12 weeks.

A report, broadcast on 19 May 2009 on SABC2 Morning Live, described an informal caregiver's programme started in 1990 called "Let us grow" in Orange Farm Ward 1 by an ex-lay counsellor Rose Thamae. This programme was started with five women who acted as a support group and as community health workers. The programme increased to 75 support persons with 1 600 HIV/AIDS infected people on anti-retroviral treatment (ARVs). The role of the community workers are to teach infected people about accepting oneself, opening up about HIV/AIDS status, how to live with the disease and providing information via an information centre. Furthermore, due to poverty and a lack of nutrition a soup kitchen was introduced. An increasing number of people were interested in HIV testing and counselling, those who tested positive, were started on ARVs. Support groups were established where most of the HIV-positive people could talk openly about their status, while some continued to be counselled.

2.4.3. COMMUNITY SOCIAL SUPPORT PROGRAMMES

HIV/AIDS infected people are faced with social problems like alcohol and drug abuse, physical abuse etc. To these infected people these are some of the ways of dealing with their illness.

Campbell (2004:5-7) researched people's lifestyles and believed that if local people participated in community-based public health projects designed to promote health-enhancing behaviours, such participation influenced health behaviours in a range of ways. People with sexually transmitted infections (STIs) are more likely to perform healthy behaviours such as accessing health services. In addition the individual's sense of perceived self-efficiency or empowerment includes taking control of their health.

According to Vithayachockitikhum (2006:123-128) in Thailand, there is an increase in the number of people living with HIV/AIDS. Consequently the demands of family caregivers who take the responsibility for the care of these patients at home are escalating. Ninety six percent of HIV/AIDS patients preferred home-based care services because they feel safe, happy and comfortable with their close relatives. In Thailand, knowledge about family care giving of people living with HIV/AIDS is sparse and research in family care giving is in its infant stages.

2.4.3.1. Isolation

The literature reveals that isolation may stem from support deficiencies and unmet support needs. There exist numerous barriers to support for people living with HIV/AIDS, family caregivers and community health workers which include interpersonal costs, negative interactions, and fear of disclosure, social stigma, acceptance and intimacy (Stewart, Hart, Tackson, Langille, and Reidy, 2001:209-255).

Although support interventions can decrease conflict, create new sources of support or alleviate social isolation, the interventions for community health workers, people living with HIV/AIDS and their families are rare.

It is for this reason that Stewart, Hart, Tackson, Langille, and Reidy (2001:209-255) conducted telephone support interventions with community health workers, people living with HIV/AIDS and their families. The advantages of telephone support are its anonymity and the ability to bring people together that are unable, geographically or logistically, to participate in a face-to-face support group.

2.4.3.2. Social stigma

According to Shaibu (2006: 89-94), community home based care (CHBC) rendered by community health workers has come to be associated with HIV/AIDS. Consequently, some families who need the services of the CHBC programme refuse to have their relatives enrolled because of the stigma associated with community health workers. Even the patients who were not HIV positive refused to join the programme. Some of the challenges that we have yet to overcome are the stigma and the convincing of communities that the CHBC programme is for all chronically ill patients. The theme for the 2002 World Aids Day was stigma and discrimination, and although this has been discussed many times it is still a problem (Shaibu, 2006: 89-94).

Thomas (2006: 3174-3187) did a study on stigma, fatigue and social breakdown. Thomas concluded that a key part of HIV/AIDS mitigation lies in meeting growing care needs and provision of support for people living with HIV/AIDS. Such support should be strengthened through the development of counselling services which address the psychological and emotional impacts of AIDS and encourage testing, disclosure and support in order to delay and help manage the onset of AIDS-related illness. Home-based care support from informal caregivers' programmes undoubtedly played a very big role in relieving the burdens of caring duties.

Stigma may involve actions such as gossip, verbal abuse and distancing from the person with HIV/AIDS, which can range from subtle actions to extreme degradation, rejection and abandonment (Bond, Chase & Aggleton, 2002: 347-356). In the study sites stigma perceived by HIV/AIDS people was openly discussed during interviews and focus groups. This stigma was caused and exacerbated by prevailing attitudes towards dependence and reciprocity, with

feelings of being tainted or discounted by others tending to increase at times when patients were too sick to be able to contribute to livelihood and familiar activities.

As Bond, Chase and Aggleton (2002: 347-356) made it clear, it is important to contextualise this stigma, recognise that fatigue and burden of care challenges the household's ability to provide treatment and support. Relating to social breakdown, the daily isolation and loneliness of patients was clearly evident. Isolation is also exacerbated by the layout of many settlements in the Caprivi, with accusations of witchcraft and subsequent family conflict resulting in wide dispersal of households.

In a situation in which motherhood is accorded significant status and value, the inability of women to fulfil their role as mothers and ensure the immediate and future well-being of their children emerged as a key concern (Nashandi, 2002: 121-130). The psychological well-being of patients was clearly influenced by the manner in which they were viewed by others. While they could feel neglected and isolated during times of dependency, their ability to contribute to the household brought an increased sense of well-being and optimism and decreased the level of stigma they perceived from others, enabling them to regain a level of self-control.

Collins (2001:351-360) did research on changes in health promoting behaviour following diagnosis with HIV. Collins specifically looked at diet, exercise, smoking and substance use patterns. Collins interviewed 2 864 people receiving HIV care. It was found that most had made health promoting changes in one or more of these behaviours since diagnosis. Many reported increased physical activity (43%) and improved diet (59%). Forty-nine percent of cigarette smokers quit or cut down, 80% of substance users quit or cut down.

2.4.4. COMMUNITY SPIRITUAL SUPPORT PROGRAMMES

Supporting the patients spiritually may encourage them to live more positively; this support may be given by credible and appropriate religious or spiritual leaders.

According to Thomas (2006: 3174-3187) religion plays an extremely important role for all patients, providing solace at times when people felt isolated from friends and

relatives. However, some church leaders have a tendency to interpret illness as a punishment for immoral behaviour. Such beliefs inevitably impact upon the well-being of ill people, who may find they are being judged by others for suspected wrong-doings or questioning their own behaviour in an attempt to understand their illness. Paradoxically, while this acceptance of self-blame can perpetuate the suffering of the ill person, it also provides a form of relief and optimism. By accepting they have done wrong, patients are able to actively attempt to rectify the situation through prayer, thus giving them hope that they will be forgiven and will recover.

As shown by Cotton (2006: 55-113), spirituality and religion are often central issues for patients with chronic illness. Cotton (2006: 55-113) did a study to examine associations between spirituality/religion, demographics, clinical characteristics, health status and a number of psychosocial variables including social support, self-esteem, optimism and depressive symptoms and also assessed changes in overall level of spirituality over a 12 to 18 months time frame. The conceptual model included a range of psychosocial, clinical and demographic variables that have been posited to be related to spirituality/religion in patients with a chronic illness such as HIV/AIDS. Seventy-five percent of participants or patients said that their illness had strengthened their faith and patients used positive religious coping strategies (e.g. sought Gods' love and care) more than negative ones (e.g. wondered whether God has abandoned me). Most patients with HIV/AIDS belonged to an organized religion and used their religion to cope with their illness. Patients with greater life satisfaction, minorities and patients who drink less alcohol tend to be more spiritual and religious.

Bush (2008: 539-545) describes spiritual care as a dimension of holistic care: a relational interpretation. Spiritual care practices have long been a feature of health care (Koenig, 2001: 1189-1191). However, questions still arise concerning how health professionals interpret the meaning of spiritual care (Wright, 2002: 125-132). Bush (2008: 539-545) explored the meaning of the phenomenon of spiritual care, as described by palliative care professionals drawn from a number of health disciplines, and seeks to capture the caregiver's perspective of spiritual care, thereby helping to add to existing descriptions of spiritual care.

All participants described spiritual care as being a key feature of their health care and related the meaning of the phenomenon of spiritual care to their professional role with the need to translate this meaning into healthcare practice. However, the nurse participants expressed uncertainty about the actual process of integrating this concept into healthcare practice. This reservation echoes McSherry's (1998: 36-41) determination that while nurses can identify a person's spiritual needs, they are not sure how to provide relevant spiritual care. Despite expressions of uncertainty about the meaning of spiritual care all of the nurse participants described spirituality and spiritual care in both religious and secular terms.

The theme, 'a living nexus between spiritual care, spirituality and holism', incorporates the dimension of spiritual care that captured the relevance of the participants' personal and professional experience in health care and helped them to construct their sense of spirituality. Participants' sense of spirituality also provided them with a meaning and purpose in life and underpinned their spiritual care. Participants described their spiritual care practices but stated that they lacked formal preparation. Their capacity to facilitate spiritual care was related also to their own sense of spirituality. All of these features were linked to a holistic model of health (Bush, 2008: 539-545).

2.5. FACTORS INFLUENCING THE SUSTAINABILITY OF CHW PROGRAMMES

Programmes should be adequately funded, be cost-effective and an awareness campaign launched to inform the community so as to ensure the sustainability of the CHW programmes.

The community should be involved in the selecting, recruiting and training of the CHWs and participate in identifying roles, defining goals, implementing actions and evaluating the process. Mechanisms for community control over CHWs should be built into programmes. Programmes should be specific, acceptable and realistic and have supportive and visionary management. Furthermore, national political commitment for the development of CHW programmes should exist (Campbell, 2004: 5-14).

CHWs should be accountable both to the community and to the local health authority/employing body. To strengthen community accountability, it is advisable that funds for remuneration of CHWs be channelled through community committees. Community health workers (CHWs), facilitators and supervisors should be accredited and career paths mapped out. Appropriate training of CHWs, community health worker facilitators, supervisors, community and local government committees would be of benefit. Adequate and effective supervision, monitoring and regular evaluations are recommended (Campbell, 2000: 182-196).

Strong links should be established with the health services and other sectors as well. The state should be involved in terms of provision of funding, legislation and implementation of mechanisms for support at all levels of the health system (Cruse, 1997: 1-40).

2.6. FACTORS INFLUENCING THE CARE GIVEN BY CAREGIVERS

According to Richter and Peu (2004:31-40) the educational and supportive needs of informal caregivers should be explored and described. This will assist in planning and establishing health education programmes and a supportive network including workshops, HIV/AIDS counselling, communication skills, and the use of community advisors such as priests who support the spiritual needs of the patient.

2.6.1. VULNERABILITY OF INFORMAL CAREGIVERS

Flaskerud (2000:121) described that caregivers were also susceptible to emotional problems when caring for patients infected and affected by HIV/AIDS. Caregivers experience distressing emotions that may affect their mental and physical health. A comprehensive approach to mental health nursing therapy will best meet the needs of caregivers in relieving their distress. Table 2.1 below shows the emotional problems experienced by informal caregivers caring for people living with HIV/AIDS, which is more than that experienced by informal caregivers caring for people with any other disease.

Table 2.1: Distressing emotions experienced by caregivers (Lee, 2001:60-68)

MOOD	CAREGIVERS OF PEOPLE WITH HIV/AIDS (%)	CAREGIVERS OF PEOPLE WITH CANCER (%)
Sad	81	78
Lonely	78	61
Depressed	87	63
Crying	69	49
Hopelessness	47	68
Life a Failure	56	15
Everything an effort	64	59
Couldn't get going	64	68
Bothered	69	66

In an interview with caregivers attending an outpatient clinic at public hospitals Lee (2001:60-68) determined the vulnerability to health problems in female informal caregivers of persons with HIV/AIDS. Predominantly mental health problems prevailed. Conditions that put caregivers at risk for a poorer health status were measured as:

- the number of years of care giving;
- hours per day in care giving;
- memory and behaviour problems in the care receiver; and
- functional status of the care receiver.

Khakha (2006:275-276) also looked at the vulnerability of community health workers and suggested the following reasons for it:

- physical stress because of being overworked;
- caring for patients with an incurable disease is emotionally draining;
- limited resources to provide the necessary treatment;
- the lack of an effective support system for community health workers;
- feeling trapped in a work situation with little recognition and few rewards for work well done; and
- being assigned more tasks than can possibly be managed.

2.6.2. SUPPORT GROUPS FOR INFORMAL CAREGIVERS

Although support groups may seem the logical answer for emotional support, there are many reasons for caution. Support groups may not be easily accessible because of a variety of common factors such as a lack of transportation and despite care, but also to other factors such as stigmatization and family desertion and isolation of the caregiver (Flaskerud, 2000:121).

Informal caregivers take care of people living with HIV/AIDS, but nobody takes care of the caregivers. Sometimes the informal caregivers are deserted by their own family members. Many a time informal caregivers are also people who are suffering from HIV/AIDS. They disclose their status to their patients and family members and then they get stigmatized. Informal caregivers also feel isolated sometimes (Lyon, 2001:129).

Mobilizing the caregiver's traditional support system whether it is the family, church or a social group might be of more benefit. Such an approach would have to include an educational component for the family, church or social group that dealt directly with stigma and moral judgements, and reluctance to discuss problems outside the family. This type of intervention is more successful when the nurse and family collaborate in defining and managing the problem (Flaskerud, 2000:121).

2.6.3. HOME VISITS FOR INFORMAL CAREGIVERS

Home visits by a community nurse or home health care worker might also be part of the case management approach. Such visits would provide an opportunity to assess the caregiver's home environment at regular intervals and then adapt and/or reinforce the teaching and counselling given during primary health care clinic visits. Home visits would provide an opportunity to further collaborate on caregiver and care receiver health problems and make changes in health services as needed. These visits would also serve to decrease the isolation and loneliness experienced by the caregiver and might have the side effect of involving additional family members in care giving (Minnaar, 2001:19-26).

2.7. LINK BETWEEN HIV DISEASE, DEPRESSIVE SYMPTOMS AND PURPOSE IN LIFE

Lyon (2001:129) examined relationships among “purpose in life”, “HIV disease serenity” and “depressive symptoms” in people living with HIV/AIDS. It was tested that “purpose in life” is a stronger predictor of depressive symptoms than is “HIV disease serenity”. This therefore indicates the need for routine assessment of depressive symptoms in people living with HIV/AIDS. “Purpose in life” should be explored as a potential buffer for depressive symptoms.

Stewart, Hart, Tackson, Langille, and Reidy (2001:209-255) conducted a pilot project testing the feasibility of a teleconference support group intervention for HIV/AIDS haemophilia patients and informal caregivers in Quebec, Canada. The composition of the sample included 3 males with haemophilia and HIV/AIDS and 4 informal caregivers, of whom two were parents and two were spouses, unrelated to the haemophiliac individuals.

The findings from the study suggested possible factors that may affect informal caregivers’ physical health and psychosocial well-being. The caregivers reported weight loss as a result of the burden of care giving. They experienced negative social attitudes; inadequate, inaccessible information and unmet needs from health and social systems; and a sense of isolation. The investigators found that the intervention increased caregivers’ sense of confidence and diminished their isolation and loneliness.

Health behaviours can either be positive which will include regular, adequate exercise, hours of sleep, taking medication or negative, which may include tobacco smoking, alcohol consumption and lack of physician follow-up (Prachakul, 2003:55-71). It is important to examine how selected health behaviours affect the care giving role and responsibilities and other outcomes, such as depression, and vice versa.

2.8 CONCEPTUAL THEORETICAL FRAMEWORK

According to Clarke (2003:3) health means being well or healthy in your body, mind and spirit and living in a healthy family, community and environment.

When infected with HIV/AIDS the individual is affected, that means there is a break in the chain of the health process. All dimensions of the individual become affected, which include the physical, social, emotional and spiritual aspects. As illustrated in figure 2.2 every human being is a four dimensional unit physical, social, emotional and spiritual being having basic needs within each dimension. An individual furthermore functions within the context of a family and community (Daniels, 2004:60-61).

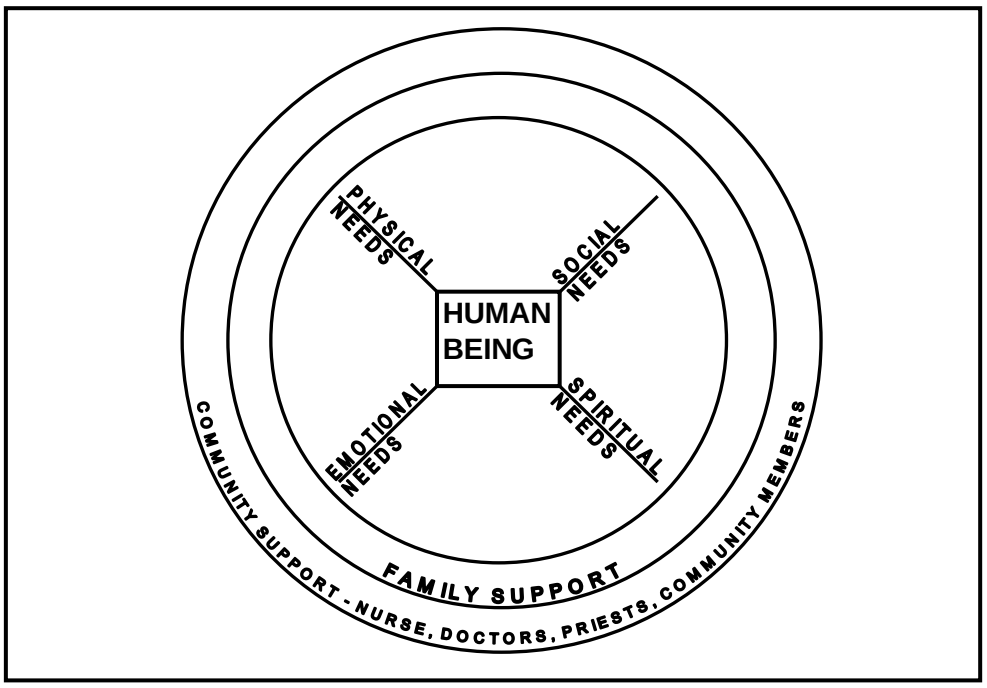

Figure 2.2: Holistic approach to human needs (Daniels, 2004:60-61)

According to Chinn and Kramer (1999:51) theory is defined as a creative and rigorous structuring of ideas that project a tentative, purposeful and systematic view of a phenomenon.

The conceptual framework used to guide this study is based on the following (George; 2002:45, 86, 98 and 176):

- Florence Nightingale's environmental model

- Virginia Henderson's theory of 14 components of basic needs
- Faye Glenn Abdellah's theory of nursing problems
- Abraham Maslow's hierarchy of needs

2.8.1 FLORENCE NIGHTINGALE'S ENVIRONMENTAL MODEL

According to Nightingale in George (2002:45) one of the most important needs of a patient is a conducive environment to individuals and their families. Various aspects of the environment is emphasised such as good lighting, nutrition and ventilation. In Nightingale's view, the environment of the patient is critical as they suffer from a debilitating disease and requires extensive support within a therapeutic environment. Good lighting and ventilation as well as a balanced diet are crucial for people living with HIV/AIDS.

2.8.2 VIRGINIA HENDERSON'S THEORY OF BASIC NEEDS

Virginia Henderson as described in (George, 2002:86) formulated a theory of 14 basic components of needs. These include basic needs such as normal breathing, eating and drinking adequately, elimination, adequate sleeping and rest, hygiene of the patient, safety and communication. These needs are directly applicable to the HIV/AIDS patient.

2.8.3 FAYE GLENN ABDELLAH

The theory described by Abdellah (George, 2002:176) emphasises twenty-one nursing problems of which the need for identification is the most important. These problems do not only concentrate on the physical needs but include social, psychological and spiritual needs. Examples of these problems are expression of feelings, lack of communication and lack of achievement of personal spiritual goals. Physical problems include: good hygiene, exercise, safety, security, nutrition and elimination. All of the above mentioned needs are very much applicable to the needs of people affected by HIV/AIDS.

2.8.4 ABRAHAM MASLOW'S HIERARCHY OF NEEDS

Maslow's theory of human needs as described in George (2002:98) is aligned with Henderson's fourteen components of basic needs. The theory is described in five levels where one level is dependent on the previous level. The most basic level is the physical needs followed by the second level of safety and security, and then the third level of belonging needs, the fourth level is self esteem and lastly self-actualization (See figure 2.3).

In summary the above mentioned three theories and one model is directly applicable to the basic needs of the HIV/AIDS patient. If these needs are disturbed the patient experiences discomfort. Comfort can be described as total well being in all dimensions, should the one dimension be affected such as in the HIV/AIDS patient, the physical dimension is affected which then influences the social, mental and spiritual dimensions (Daniels, 2004:60-31).

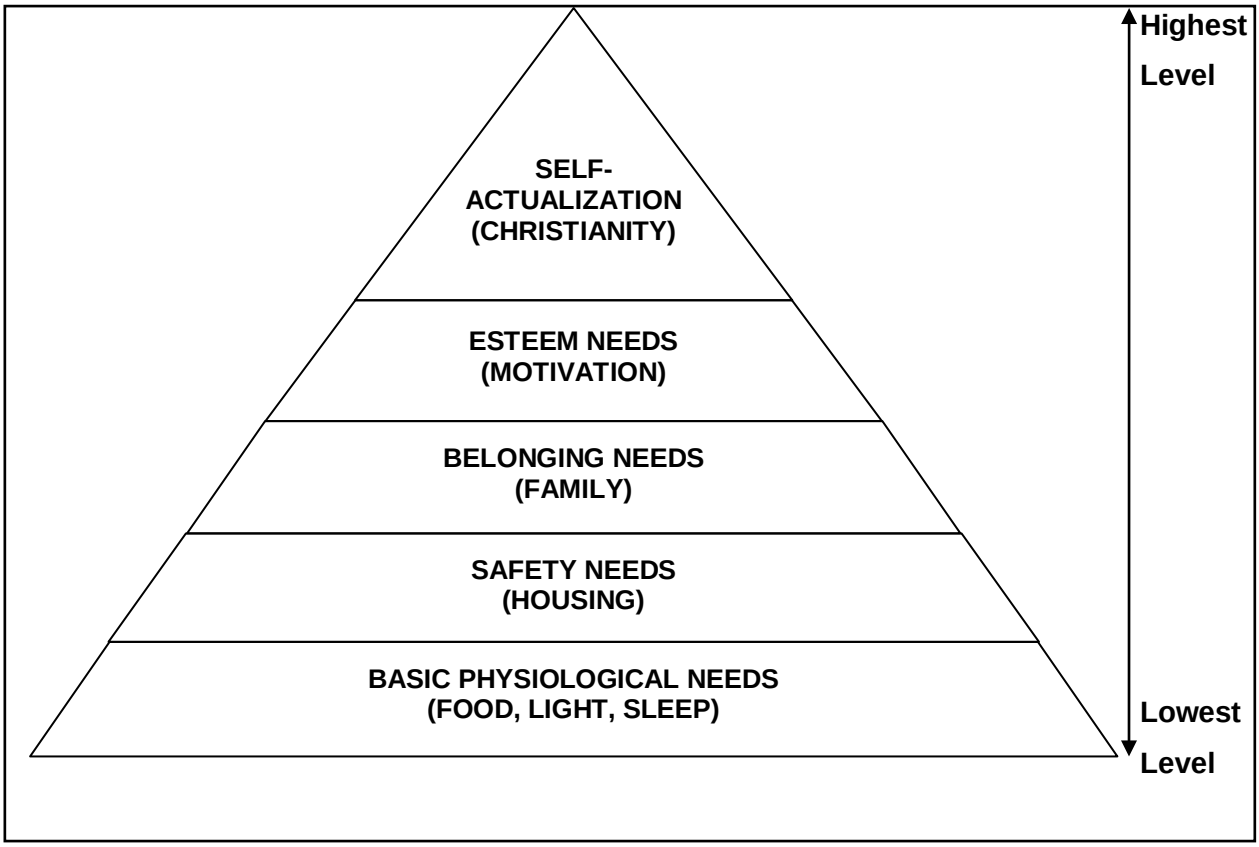

Figure 2.3: Maslow's work directed at all four aspects of life - physical, social, emotional and spiritual (Figure by the researcher).

2.9. CONCLUSION

In this chapter, an in-depth literature review regarding community health workers was described with specific reference to the definition of community health workers, community based support programmes, palliative care and the factors influencing the sustainability of community health worker programmes.

In the next chapter, chapter 3, the purpose and objectives will be described including the research methodology applied in this study with emphasis on the research design, validity, data collection, data analysis and the limitations of the study.

CHAPTER 3

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In the previous chapter the literature related to community health workers and the theoretical conceptual framework for the study was described. In this chapter the researcher proceeds to describe the research methodology implemented for the study including the purpose, and objectives of the study.

According to LoBiondo-Wood and Haber (2006:6), the professional nurses are constantly challenged to stay abreast of new information and to provide the highest quality of patient care.

3.2 PURPOSE OF THE STUDY

The aim of this study was to evaluate the effect of an informal caregiver's programme on the care of patients infected with HIV/AIDS.

3.3 OBJECTIVES

The following objectives were set to evaluate the effect of the care given with reference to:

3.3.1 emotional care
3.3.2 spiritual care
3.3.3 social care
3.3.4 physical care
3.3.5 informational and educational support

3.4 RESEARCH QUESTION

The researcher posed the following research question which guided the study: “What is the effect of an informal caregiver’s programme on the care of patients infected with HIV/AIDS?”

3.5 RESEARCH APPROACH AND DESIGN

The researcher followed a qualitative approach which means that the findings were not arrived at by means of statistical procedures or other means of quantification, but by phrases or words (Strauss and Corbin, 1990:17). Qualitative research is a process of inquiry with the goal of understanding social or human problems from a multiple perspective, conducted in a natural setting with a goal of building a complex and holistic picture of the phenomenon of interest (c:\myfile\curriculum\chapter4.fnl.wpd). The researcher through a trained fieldworker was able to obtain in-depth living experiences from the patients related to the various aspects of care of the programme offered to them.

A phenomenological research design was applied to evaluate the effect of an informal caregiver’s programme implemented for the care of patients infected with HIV/AIDS at Mfuleni Township of the Cape Metropolitan area. The aim of a phenomenological design was to describe qualitatively an in-depth experience of the various aspects of the care given. The phenomenological approach best supported the exploration of lived experiences (Burns and Grove 2003:360). According to Trochim (2006: np), “Phenomenology is a school of thought that emphasizes a focus on people's subjective experiences and interpretations of the world…” It could be interpreted as the phenomenologist wanting to understand how the world appears to others.

3.6 POPULATION AND SAMPLING

For the purpose of this study patients being cared for by caregivers who participated in the informal caregiver’s programme, were eligible to participate in

the study. Fifteen (15) patients participated in the caregiver's programme in the Mfuleni area.

A simple random selection was done by drawing ten (10) names from a hat. The sample included seven (7) females and three (3) males between the ages 31-57 years with a mean age of 42 years. All participants were from the Mfuleni area which is predominantly a Xhosa community environment. The education level of the participants varied between no schooling and grade11. All participants except two received both TB and anti-retroviral treatment. Five of the ten participants became bedridden in 2008 and required intense support; currently only two are bedridden and are not able to attend a clinic to obtain their treatment.

3.7 SPECIFIC CRITERIA

- Participants who were not only infected with HIV/AIDS but affected by the disease.
- Participants who participated in the informal caregiver's programme for a period of 3-12 months.
- Participants being cared for in the Mfuleni area.

3.8 INSTRUMENTATION

An open ended semi-structured interview schedule (See annexure A, page 81) was designed to collect the data. According to De Vos et al. (2005:296), an interview guide or "schedule" is a list of questions used by the interviewer to explore during each interview.

In qualitative studies, the interview format is more likely to be open-ended. Although the researcher defines the focus of the interview, there is no fixed sequence of questions. The questions addressed in interviews tend to change as the researcher gains insight from previous interviews and observations. Respondents are allowed, even encouraged, to raise important issues not addressed by the researcher. During interviews for qualitative studies, the researcher and the participant are actively engaged in constructing a version of the

world. The interview is performed so that a deep, mutual understanding is achieved. The researcher's goal is to obtain an authentic insight into the participant's experiences. Rather than occurring at a single point in time, dialogue between researcher and participant may continue at intervals across weeks or months. Having recurring interviews should decrease the problems associated with fleeting relationships, in which respondents may have little commitment to the study or may provide only the information they believe the researcher wishes to hear (De Vos et al., 2005: 296).

3.9 DATA COLLECTION

The sample of ten participants was each allocated a numeric number. Microsoft Excel was used to randomly allocate these names in a chronological order for data collection to determine who will be interviewed first. Each name was then given a number to maintain anonymity and confidentiality. Data collection started at number one and continued until all ten (10) participants were interviewed. After the eighth interview data obtained was very similar. The participants were reporting similar experiences about the caregivers caring for them.

To prevent bias a trained fieldworker interviewed participants individually because the researcher was personally involved in the training of the caregivers and patients. Data were collected using face-to-face, semi-structured in-depth interviews. The duration of the interview varied between 30 minutes and 45 minutes. The duration was subjected to the amount of information a participant shared with the fieldworker. Some of the participants only communicated what was asked while some just talked, opening up to the fieldworker. The interview was guided by the following interview schedule or guide:

- Tell me everything that the caregivers have done for you, pertaining to emotional, social, educational and spiritual support?
- Do you consider the care given to you by the community health worker to be helpful? Why?
- Give your understanding of what the informal caregiver's programme is all about.

- What more can be done for you?

One question was asked at a given moment and the participants were given an opportunity to answer each question individually.

Interviews were tape-recorded and transcribed verbatim. Interviewing was terminated after the 10th participant, when no new descriptions were forthcoming an indication that data saturation was achieved. Participants were interviewed individually in their own homes. They all appeared to be relaxed, comfortable and willing to talk about their experiences. However, one cried during their interview when talking about very emotional and painful issues. Although strategies and a plan of action were devised before the interviews in the event of a participant showing signs of distress, these were not required. All participants assured the interviewing fieldworker that they felt better as a result of sharing their experiences except for two male participants who regarded the interview as being intimate and withdrew. The researcher then decided to include an additional two participants who met the criteria and who volunteered to participate after two males withdrew. Refocusing questions were used when necessary to clarify meanings during the interviews.

3.10 DATA ANALYSIS AND INTERPRETATION

The researcher analysed the data by listening to the tapes and transcribing the individual participant's recorded interview. Data was explored in detail for common themes and patterns. These were then established into units of means or codes. The verbal responses of the researcher's notes and the transcribed interviews were captured onto a master file on a Microsoft Word document immediately after each interview. Observations of non-verbal cues that were noted in the diary were also recorded. A colour code index using "highlighting" of the phrases was used to identify the different themes that evolved. Themes were added until saturation was met. The themes were continuously compared to the available literature around the experiences of participants in relation to the care given.

According to Pope, Ziefland and Mays (2000:220), the analysis of qualitative data is not "…a simple or quick task…" It is firstly time consuming, a rigorous and systematic, process and therefore labour-intensive. Fielding in Pope, Ziefland and Mays (2000:220) contends that "good qualitative analysis is able to document its claim to reflect some of the truth of a phenomenon by reference to systematically gathered data"; in contrast, "poor qualitative analysis is anecdotal, unreflective and descriptive without being focused on a coherent line of inquiry".

3.11 MEASURES TO ENSURE TRUSTWORTHINESS

The principles of trustworthiness as described by Lincoln and Guba (1985:29) in chapter 1: credibility, transferability, dependability or conformability were applied. Brief descriptions of these principles as applied in the study are now described in chapter 3.

3.11.1 CREDIBILITY

According to De Vos, Strydom, Fouche and Delport (2005:346), credibility is the "... alternative for internal validity in which the goal is to demonstrate that the enquiry was conducted in such a manner as to ensure that the subject was accurately identified and described."

To have ensured that credibility of the study was maintained clear and specific parameters for the study were set. The purpose of this study was to evaluate the effect of an informal caregiver's programme on the care of patients with HIV/AIDS. Only subjects who were participants in the programme introduced for the Mfuleni Comprehensive Clinic and Dr Ivan Tom's Clinic were included in this study and were involved in the programme for a period of 3-12 months. In addition experts in the field of nursing and research methodology were consulted to determine the feasibility and content of the study, to evaluate the research process and outcome. The researcher also presented the planned proposal at the master's degree critique forum before it was finally presented to the ethical committee of the university. Internal validity / truth-value or credibility was further assured by the

satisfaction of the participants who understood the questions and agreed with the way it was interpreted.

3.11.2 TRANSFERABILITY

According to Lincoln and Guba (1985:19-22), this is the alternative to external validity, however as described by De Vos et al. generalization is problematic in qualitative research. However as described in De Vos (2005:346) by introducing a theoretical conceptual framework to guide the study the research findings becomes generalisable.

Therefore to counteract the problem of generalisation in qualitative research the researcher formulated a theoretical foundation for the study based on the basic needs of patients or individuals. The conceptual theoretical framework for this study is based on the models and theories of Florence Nightingale who described the therapeutic environment within which the patient must be nursed; Henderson, Abdullah and Maslow who describe how the basic needs of patients are to be met. Based on the conceptual theoretical framework the principle of transferability will therefore be ensured when the findings of this study are applied to other HIV/AIDS patients who need to be cared for by informal caregivers. To ensure consistency similar findings will be obtained if the study is repeated in a similar study i.e. patients being cared for in an informal caregiver's programme.

3.11.3 DEPENDABILITY

Dependability is referred to as the alternative to reliability as used in quantitative research although very different in qualitative research as the social world is constantly changing. For the purpose of this study the researcher ensured consistency / dependability by the meticulous recording and taking of notes during and after the interviews with participants and using the same technique in conducting each interview. The same interview schedule was used and additional questions were allowed as the in-depth discussion progressed. Data was transcribed and analysed after every interview. The experiences of participants who participated in the informal caregiver's programme were accurately described

or interpreted. For this purpose the use of a tape recorder was used to ensure that all information as described by the participants was captured. Any non-verbal communication was also noted.

3.11.4 CONFORMABILITY

A fieldworker was trained to ensure that objectivity / neutrality / conformability were maintained to exclude bias due to the researcher's involvement in the introduction of the programme. In addition a reflective diary was kept by the fieldworker to have ensured that the fieldworker remained neutral when probing into the participant's lived experiences. Furthermore, after transcribing each participant's data it was verified with the particular individual to ensure that the data was transcribed accurately and that bias was excluded.

3.12 PRE-TEST OR PILOT STUDY

According to De Vos (2005:331), in qualitative research it is critical to complete a pilot study to allow the researcher to focus on specific areas or to test specific questions which may have been ambiguous or unclear. According to Monette, Sullivan and de Jong (1998:9), a pilot study can be regarded as a small-scale trial run of all aspects planned for use in the main inquiry. Mitchell and Jolley (2001:13-14) add that a pilot study helps the researcher to fine tune the study for the main inquiry. Substantiated further, Bless and Higson-Smith (2000:155) describe a pilot study as "…A small study conducted prior to a larger piece of research to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate".

For the purpose of this study a pilot study was conducted which included one patient who was selected at random to evaluate whether the open ended structured interview schedule (Annexure A) do indeed stimulate in-depth retrospection and discussion. The researcher received consent and interviewed one patient, who met the criteria set for the study namely being HIV/AIDS infected and who participated in the informal caregiver's programme. The participant spoke openly about her status and was eager to be interviewed, exploring feelings and

experiences about care received through the informal caregiver's programme. The results of the pilot study showed that the study was feasible and the use of the interview schedule was appropriate and accurate for the purpose of this study.

3.13 LIMITATIONS OF THE STUDY

Limitations which occurred in the study included the following:

- Initially most of the participants refused to talk about their status but as the communication progressed participants were more open.
- Two of the male participants refused to talk to a female fieldworker about their private lives and withdrew from the study.
- Cultural aspects such as not making eye contact with the researcher were dominant and were a hindrance in non-verbal communication.

3.14 CONCLUSION

This chapter described the purpose, objectives of the study and research methodology which were implemented for this study. This included the research design, population and sampling, validity and trustworthiness, data collection and data analysis. In the next chapter the data analysis are described.

CHAPTER 4

DATA ANALYSIS, INTERPRETATION AND DISCUSSION

4.1. INTRODUCTION

This chapter describes qualitatively different ways of experiencing the patient's interaction with the informal caregiver. It serves to determine the effect of the programme by exploring the patient's "lived experience" about the care given to them.

Analysis goes beyond description, using methods to transform the data. Through this process, the researcher extends the data beyond the description. Using analysis, he or she identifies essential features and describes interrelationships among them (De Vos et al., 2005:334).

Vollenhoven (2008:32) suggest that by "reading through data extracts, one might discover particular events, key words, processes or characters that capture the essence of a piece."

4.2. RESULTS OF DATA ANALYSIS

Each participant was identified by the use of codes between one and ten. Patients described their "lived experience" about care given to them. The researcher applied the eight steps for data analysis as proposed by Tesch (1990:154-156) and supported by De Vos et al., (2005:334).

In the first step the researcher read through all the transcriptions carefully and got a sense of the study in its totality and during this time ideas were written down as they arose. During the second step the researcher selected one interview and thoroughly studied the content of the interview and posed the question by asking "What was this about?" and simultaneously thinking about the underlying meaning in the information. Various thoughts and patterns emerged from the interviews and all thoughts were written down as a list of themes which were categorized.

The themes were abbreviated as codes and were written next to the appropriate segments of the text. The researcher tried out the preliminary organising scheme to see whether new themes and codes would emerge.

- The researcher found the most descriptive wording for the topics and turned it into themes. The researcher then continued to reduce the total list of themes by re-grouping together topics that related to each other. Lines were drawn between the themes to show inter-relationships.
- The researcher made her final decision of the abbreviation for each theme and it was coded.
- The data material belonging to each theme was assembled in one place and a preliminary analysis was performed by testing for any emergent understandings and searching for alternative explanations.
- The researcher recoded existing data where necessary.

The study took place in a community of low-socio-economic status, where a high unemployment rate as well as financial burden was a major problem. Nine of the participants were unemployed; only one participant had a part-time job. The majority of participants depended on their short periods of getting grants; some depended on their children and family members to feed them.

Only two participants had children older than 18 years who were working, but they also had their own families. Three participants also had children older than 18 years, but they were unemployed. Once a month participants received food parcels, from an organization called Ma-Africa Tikkun, which were brought to the participants by the community health workers (CHWs).

The various themes that were derived are the following: - physical care, social care, spiritual care, emotional care and informational and educational support.

4.3. THEME 1: PHYSICAL CARE

HIV/AIDS has a major impact on an individual's physical functioning and household well-being, thus putting tremendous physical pressures on HIV/AIDS infected individuals and their families. This physical functioning includes the following (Cunningham, 2008:844):-

- Vigorous activities such as running, lifting of heavy objects and participating in strenuous sports.
- Climbing flights of stairs.
- Walking for more than a kilometre.
- Walking one block.
- Bathing or dressing of one self.
- The preparation of meals or doing the laundry.
- Doing the shopping.
- Getting around inside the house.
- Feeding one self.

When asked during the interview about the help participants received from CHWs, these were the typical comments from the participants:-

Participant 1: “I was mentally disturbed, but stable when I first met the CHW. I had swollen feet and all my kids were still very young (2-15 years) at the time. The CHW was very helpful to me. She would come visit me regularly. She comes in the morning and washes and dresses me, elevate my legs. Sometimes she cooks food for me. We sit and talk she is never in a hurry. She always makes sure that I take my medicine. She puts me back in bed before she leaves and put some food in front of me. Sometimes the CHW brings food parcels for me.”

Participant 2: “CHW is not helpful when it comes to helping me clean my house; by the time she comes and visits me my house is already clean. The only time that she will help me is when my feet are swollen. I have a heart problem and was admitted to the intensive care unit at Tygerberg Hospital and then discharged in May 2009. The first two months after my discharge my feet were swollen, so that was the only time that the CHW would cook food for me and clean my house but now I clean my own house. She visits often though – at least I have someone to talk to during the day. ”

Participant 3: “The CHW is like my own sister, during my admission in Tygerberg Hospital, the CHW would come and visit me regularly. At home for the first two months after discharge, she would come to my place almost every day. She’ll

come and wash me, open the windows and brush my teeth and my hair and change my position. She will also give my children food and wash them. She also brings food parcels for me and my children. She is my hope."

Participant 4: "The CHW visits us (I and my wife) on a regular basis. If my wife is busy cleaning the CHW helps her out. The CHW and my wife mostly talk about female stuff like losing weight, relaxing of hair and so on. The CHW advises us on how to get a job and how to do curriculum vitae as my wife has passed standard 10."

Participant 5: "I am a diabetic and have high blood pressure. The CHW would advise me on what to eat and what not to eat. Sometimes my feet get so swollen that I can hardly move. I was also involved in a car accident and my arms were injured – as a result I cannot look for a job. After my discharge from hospital the CHW would come and visit me and help my partner to wash and dress me, put me out of bed and cook for me. The CHW would rub and elevate my feet. She emphasizes the importance of taking my treatment regularly. She also brings food parcels for us."

Participant 6: "I have a problem with my liver and my heart and I am also a diabetic, so my legs and feet were always swollen and painful. The CHW knew exactly what her job was and that is rubbing my feet. My daughter goes to work every morning, when she leaves I would wake-up and do my washing and cleaning of the house without my daughter knowing. I know that I am naughty but I am used to doing my own things my own way. By the time the CHW arrives at my house the first thing I do is complain about my painful, swollen legs. One day I was caught, the CHW found me doing my washing; she then spoke to me about taking care of my own health. The CHW would come sometimes to do my washing, clean the house and we cook and chat. She is very helpful."

Participant 7: "I knew I was HIV positive and on treatment but at some stage I felt very sick as a result I was just getting weaker and was bedridden for some time. Then I was also diagnosed with tuberculosis. When I was bedridden, the CHW would give me a sugar and salt solution and small frequent meals as I had

diarrhoea and was vomiting. The CHW was very patient with me – she will wash and dress me, frequently she'll change my positioning and rub my back. She'll give me my treatment. She brings me food parcels at times. Over weekends she'll come and see how I am doing. She'll stay with me for most of the day until my child comes back from school, as my brother and sister-in-law was working. One day I also want to work with people who are HIV positive and help them just as the CHW helped me."

Participant 8: "The CHW gives me love, warmth and takes care of me like her own mother. She comes to my house in the morning; ask how I slept whilst she's making tea for us. She opens the windows, makes breakfast for me and starts cleaning the house. She does my washing and makes sure that I am clean as well. If it is my time to go to the clinic she fetches me at home and brings me back home. When I've got pain and can't sleep well, I inform her. She comes to my house anytime to help, I am happy with her. The doctor referred my wife to Tygerberg Hospital fertility clinic; she goes often for her appointments."

Participant 9: "I had a stroke in 2005 and was run over by a car in 2004 and I'm still crippled, using a walking stick and unable to function properly. I stay with my sister who is at work during the day. The CHW would come in the morning help me clean the house, wash my children and cook for us. The CHW is of great help, especially as I cannot do my washing myself. The CHW comes to see me as often as possible. She will bring food for me from her own home and food parcels as well. The CHW always confirms how I feel – we do exercises sometimes. We always take a walk before she leaves and she will tell me to look after myself. I enjoy her company."

Participant 10: "At the time when I was assaulted by my partner, the CHW would come every morning to wash and dress me – my brother was afraid of touching me. She will do my dressings daily; feed me slowly taking her time – not in a rush at all. The CHW is my nurse – she has all the patience in the world. We would talk about anything and everything. She will take me for my appointments at the clinic."

Table 4.1: Theme 1: Physical care received

Subthemes	**Number of participants**
Subtheme 1A: *Personal and Family Care*	
Washed by CHWs	6
Dressed by CHWs	4
Elevation of legs	3
Put in and out of bed	2
Changing of position	2
Doing of exercises	1
Bathing of participants' children	2
Subtheme 1B: Nutrition	
Cooked for by the CHWs	6
Fed by CHWs	1
Bringing of food parcels	10
Subtheme 1C: Domestic Chores	
Cleaning of the house	4
Doing of laundry	3
Subtheme 1C: Managing Treatment	
Sugar and salt solution given for diarrhoea	1
Taken to and from the clinic	2
Dressing of wounds	1
Giving medication	2
Infertility	1

Becky et al. (2004:496-502) supports the importance of the physical support CHWs give when assisting with household chores, preparation of meals and the giving of medication to treat opportunistic infections.

CHWs were of help to the participants by taking good care of the participants. The CHW attended to the basic needs of the participants and would go beyond that. Quoting the participant's own words: "The CHW gives me love, warmth and takes care of me like her own mother." The CHW does the house chores, looks after the participants' personal hygiene; if the participant had diarrhoea the CHW would treat the patient with a solution of sugar and salt. The CHW gave advice wherever necessary and educated family members on how to take care of participants. Any

problems the participants encountered, that were beyond the CHW scope of practice and experience, the CHW would refer participants to the clinic. A summary of the themes regarding physical support are captured in table 4.1.

4.4. THEME 2: SOCIAL CARE

The majority of the participants are faced with social problems such as excessive alcohol consumption; to the participants this was one of the ways of dealing with their illness. The CHWs helped participants deal with their social problems by making use of the resources available to them.

Typical comments reported in this category include:-

Participant 1: “I had a drinking problem, I would drink beer with every cent that I have. Firstly because I just couldn’t accept my status and secondly because I was physically abused by my partner. The CHW managed to get me to the A.A. (Alcohol Anonymous); she also encouraged me to report the physical abuse to the police which I did. Today I am sober and free from physical abuse and it’s all because of the CHW. The CHW encourages me to look for a job and not to depend solely on the grant money. I thank the CHW from the bottom of my heart.”

Participant 2: “I didn’t have an identity document (I.D.) before, which is why I couldn’t get a grant – I am crippled and qualify for the grant. The CHW came to speak to my sister one day, she gave us money and we took the taxi to home affairs for me to apply for an I.D. The CHW spoke to the doctor about my children who are not getting grants – we are waiting for the doctor’s response. It’s all thanks to the CHW.”

Participant 3: “I used to get a grant temporarily, now my CD4 count is more than 200 and I am no longer getting a grant. I am old and in no position to work anymore and would like the CHW to speak to my doctor so that I can get a grant again, although my children support me.”

Participant 4: “The CHW encourages me to go out often and socialize with other people. I don’t work at the moment, but soon I will be doing a part time job and it’s all thanks to the CHW as she is the one who found the job for me. I would also like to work with people who are HIV positive when I am free and not working on certain days. I would like the CHW to please help me with that.”

Participant 5: “As a traditional healer I sometimes meet people who are drug or alcohol abusers, some are physically abused – I normally speak to the CHW about such cases and she will advise me on proper referrals. I used to smoke a lot of tobacco – it was the CHW who asked me to smoke cigarettes instead at least 6 times a day and to brush my teeth often with Colgate. I would like to be on the grant permanently like before as arranged by the CHW.”

Participant 6: “The CHW would always quarrel with me about my resorting to alcohol each time I have a problem. The CHW arranged that I attend A.A. programs. I drink less now, sometimes not at all for a period of 6 months. At some stage the CHW threatened to take my kids to a social worker because I am always drunk and did not have time for them, but now I can take good care of my children again.”

Participant 7: “We are struggling to get kids, we do not have any and the CHW informed the doctor about our problem. Participant 8: “I used to have a problem with my daughter, she wouldn’t sleep at home or she comes home late – whenever I talk to her she will talk back. The CHW helped me a lot in this regard. She will spend time talking to my daughter about the possibility of her contracting HIV/AIDS if she sleeps with male friends when she did not know their status. The CHW arranged that I could see a social worker through the help of the doctor, to get a grant for my two small children.”

Participant 8: “The CHW advised us on how to do a CV, as my wife passed standard 10 and is looking for a job.”

Participant 9: “The CHW arranged that I could get a grant. I asked the CHW to look for a place where I can do handwork like the sewing of clothes. Whenever I have a problem with my partner or daughter she intervenes. I used to use a lot of stuff and traditional medicines, the CHW helped me with that. I used to stay in a shack and

the CHW gave me the contact numbers of people I need to talk to for me to get a RDP house."

Participant 10: "For sometime after the death of my parents I was mentally unstable and as a result I could not take good care of my children. The CHW arranged for my children to stay with a very close friend of mine. Often my partner would physically abuse me – I reported my partner to the police through the assistance of the CHW. I now stay with my children and partner and I am happy because of the help from the CHW."

Table 4.2: Theme 2: Social care received

Subthemes	**Participants**	**Help Received**
Subtheme 2A:Social habits		
Alcohol abuse	3	Alcohol Anonymous
Physical abuse	3	Reporting it to the police
Drug abuse	1	Counselling
Smoking a lot	1	Counselling
Bad lifestyle	1	Referral to clinic
Subtheme 2B: Social problems		
Stigmatization	10	Socializing more
Unemployment	2	Getting a part-time job
Curriculum vitae	1	Helped
Housing	1	Getting a RDP house
Subtheme 2C: Cultural belief		
Traditional medicine	1	Referral to clinic

Campbell (2004:5-7) looked at peoples' lifestyles and believed that if local people participated in community-based health projects then people are more likely to perform healthy behaviours such as accessing of health services with sexually transmitted infections.

Socially CHWs helped participants by making use of the resources which are available to them. They advised participants whom to contact and many times the CHW would accompany the participant. CHWs acted as advisors or rather as the

middleman for the participants. A summary of the themes regarding social support are captured in table 4.2.

4.5. THEME 3: SPIRITUAL CARE

Supporting the patients spiritually may encourage them to live more positively; this support may be given mainly by credible and appropriate religious or spiritual leaders. Patients should be encouraged to engage in religious and spiritual practices of their beliefs which include prayers, meditation and the reading of spiritual material, acts of worship, ritual forgiveness and service.

Typical comments reported in this category include:-

Participant 1: “The CHW is helpful, she enquires about things. We always talk about going to church – she will ask me what church I attend and how often do I go to church. We will talk about the positive impact the church has on people, for example I was a drinker and now I have stopped drinking because of the church. The CHW stresses the importance of trusting God in everything that we do. We have sessions about HIV/AIDS and other illnesses on Wednesday in church, but I do not have taxi money to go to church every Wednesday.”

Participant 2: “The CHW would talk to me about the importance of going to church but because she knows that I cannot go to church regularly as I am crippled, she will pray with me before she goes home. The CHW encourages me to read the bible each day and pray for myself, my children and my family.”

Participant 3: “What I observed is that the CHW and I have something in common – we both love going to church. She will ask me about my church and the programmes that the church have; like visiting the sick in hospitals and at home. My problem about my church is that my minister never visited me at home while I was sick and he was aware that I was sick.”

Participant 4: “The CHW likes to talk about the importance of attending church services. I am a Christian; church keeps me safe from all ‘evil’ things and helps me to deal with my illness. I would like the CHW to speak to my church leaders to have

HIV/AIDS programmes in place as we do not have any. I would also like the CHW to inform my minister to visit us at home when we are sick and pray for us."

Participant 5: "The CHW often sings with me the traditional songs and mix that with gospel songs and at the end we will both pray. I am a Christian and I believe in prayer."

Participant 6: "I do not go to church regularly. Sometimes I do not see the need to go to church if my minister could not even come for one day and visit me when I was sick. Having said that the CHW made me see that I do not go to church for the sake of my minister but I go to praise God for standing by me in my illness. The CHW taught me the importance of putting God first in all of our problems; she will quote some verses from the bible that strengthens my spirit."

Participant 7: "The CHW does not talk about church much as she herself, just like us, does not go to church regularly."

Participant 8: "Just like the CHW I love going to church, the minister never comes to my house, but that is fine as I have the CHW to talk to. The church does not really play a role in caring for us HIV positive people and there are no church programmes about HIV/AIDS. I would love the CHWs to address this to our ministers – we need the minister and the churches help too."

Participant 9: "We talk about the importance of going to church and I would explain to the CHW that the church uplifts my spirit and the church members are supportive."

Participant 10: "The CHW does not talk about going to church when she visits me. I do not go to church regularly, though I do believe in God."

Table 4.3: Spiritual care received

Subthemes	Number of
Subtheme 3A: Church activities	
Attending church	5
Trusting in God	4
HIV/AIDS programmes/sessions	1
Prayer	8
Reading of the Bible	1
Visits from the minister	0
Singing gospel songs	1

Spirituality and religion are central issues for patients with a chronic illness. Most patients with HIV/AIDS belonged to an organized religion and use their religion to cope with their illness (Cotton, 2006:55-113).

All the participants believed in God although not all of the participants attended church regularly. The CHWs would talk to participants about the importance of going to church. In addition the CHWs showed participants that going to church is also a means of dealing with the acceptance of their illness, dealing with their depressive feelings of boosting their morale or self-esteem. One participant said, “The church uplifts my spirit.” This simply means that whenever the participant feels down the church uplifted her spirit, resulting in a positive feeling about herself and her illness. What is lacking spiritually is the ministers’ unavailability for participants, most of the participants complained about this. A summary of the themes regarding spiritual support is captured in table 4.3.

4.6. THEME 4: EMOTIONAL CARE

Emotional care entails being sensitive, understanding, providing a conducive environment for the patients to be able to communicate their anxieties and fear, deriving comfort by being gentle and sympathetic to patients and increasing the ability of patients to take better care of themselves. This support results in patients being able to accept and deal with their illnesses.

Typical comments reported in this category include:-

Participant 1: “The CHW is a God sent, always when we meet she will ask how I am feeling, how am I accepting my status. She will always encourage me to talk about my feelings. It is good to have someone to confide in, someone I trust and have confidence in. She comforts me by saying that I should always remember that I am neither the first nor the last person to be HIV positive and that I should not be ashamed of my status. She has a certain way of calming me down. I have accepted that I am HIV positive and that HIV is part of my life, but that it is not the end of the world. The CHW is helpful; she is my inspiration and my reminder.”

Participant 2: “The CHW always confirms how I feel about my status and how I am coping with it. She will tell not to bother myself about what people say as anybody is at risk of contracting HIV/AIDS. My neighbours were the ones who will always laugh when they see me and comment about my status, which used to bother me a lot. I used to cry a lot about this, but now I am getting used to the negative comments.”

Participant 3: “I used to talk to anybody I thought I could trust about my status, to me it was a way of trying to ventilate how I feel about my status. The CHW would ask me not to inform everybody about my status – as I do not owe anybody any explanation about my status. The CHW would ask me to talk to my minister if I feel comfortable about it. The CHW even volunteered that I talk to her any time I feel like it. If the CHW was not there, things would have been even more difficult. The CHW always listens. I am part of the support group at the clinic formed by CHWs.”

Participant 4: “The CHW is my inspiration and is very helpful to me. We would talk of how I cope with my HIV positive status. The CHW would encourage me to be positive; she would tell me that being HIV positive is not the end of the world. I can be HIV positive but live for a very long time and still enjoy my life – after all life must go on.”

Participant 5: “The CHW would say whenever I feel down I must pray and open the Bible and read any scripture that is relevant to my situation at the time. The CHW accepts who I am. I trust her; she is my friend, my helper and my problem solver.”

Participant 6: “The CHW always asked how I feel and if there is anything I want to talk to her about. She will inform me that resorting to alcohol is not a solution and that I must talk to her or to someone else I trust. The CHW is always a shoulder to cry on. Talking to her makes me feel better and relieved.”

Participant 7: “The CHW visits us (my wife and me) regularly. We talk about how we feel about our status. When we have an argument she makes us come to an agreement. The CHW made a deal with us – the fact that we are both HIV positive means not to blame each other. The CHW gave us clarity and hope about our status. The CHW communicates with us and encourages us. I have accepted my status and I live positively – after all life must go on.”

Participant 8: “The CHW is my hope, she is like my own sister – we talk about anything and everything. I have her cellphone number so that I can call her whenever I need something or whenever I need to talk to her about something that is troubling me. I cry and laugh when I want to. I attend the support group at the clinic and I just feel that I am not alone – we talk, cry and laugh together.”

Participant 9: “We talk of how I feel about my status; the CHW helped me to talk openly about my status and she encourages me to accept my status. The CHW is somebody that I can trust and always talk to.”

Participant 10: “We talk about my acceptance of my status, that it is not the end of the world and that I should not bother myself about what other people say – I should only focus on getting better. The CHW is my friend and my problem solver.”

Table 4.4: Emotional care received

Subthemes	**Number of**
Subtheme 4A: Emotional support	
Coping with status	10
Acceptance of status	10
Expression for feelings	10

Stewart, Hart, Tackson, Langille and Reidy (2001:209-225) supports the importance of emotional support as he introduced a telephone support group namely, intervention for persons with HIV/AIDS and family caregivers. Participants believed that they benefited from sharing information and support groups had decreased their feelings of isolation and loneliness.

The CHWs played a very important emotional role to the participants. They were very supportive of the participants; not only through the support groups but by visiting the participants at home. They were always within easy reach of the participants. Participants felt free to communicate with the CHWs because they trusted them. CHWs were always friendly towards participants. Furthermore, the CHWs were comforters to the participants as they allowed participants to cry if they felt like it. They were always available for participants when they felt down and required somebody to talk to. The CHWs helped participants to accept their status and to live positively with it. One participant said, “The CHW is a God sent she is my inspiration.” Another participant said, “The CHW always tells me that being HIV positive is not the end of the world, I can be HIV positive but still enjoy my life – after all life must go on.” The other participant said, “I trust the CHW she is my friend, my helper and problem solver. I have accepted my status because of her.”

4.7. THEME 5: INFORMATION AND EDUCATIONAL SUPPORT

Three of the participants never received any formal schooling. Three of the participants’ highest level of education was grade 6, two was grade 8, one was grade 9 and one was grade 11.

Typical comments reported in this category include:-

Participant 1: “The CHW and I do the pill count each time she visits me to make sure that I take my treatment correctly and regularly. We talk about HIV/AIDS; what it is, the signs and symptoms, how the disease is contracted and the importance of safe sex e.g. by condomising. The CHW is my educator.”

Participant 2: “The CHW and I we always talk about HIV/AIDS – how I contracted HIV and how to prevent further re-infection. The CHW stresses the importance of taking my treatment as prescribed, to eat first before taking my treatment and not to forget to take my treatment. The CHW keeps on informing me that HIV/AIDS cannot be completely healed.”

Participant 3: “The CHW and I we talk about my treatment – how I should take my treatment and when to take my treatment and she brings my treatment from the clinic. When I am not sure of how to take my treatment she reminds me, she also reminds me of my follow up dates at the clinic. We talk about the link between TB and HIV/AIDS. I wanted to know how come I had TB and not so long after that that I was informed that I am HIV positive. The CHW gave me an explanation about the soldiers of the body that becomes weak because of HIV/AIDS making my body susceptible to any disease. The CHW is my teacher.”

Participant 4: “The CHW would endorse the importance of taking my treatment regularly, not to default treatment. Also not to take my treatments with alcohol and not with forever products and not with traditional medicines. We talk about the importance of taking my TB treatment. Having one sexual partner and condomising is the message that the CHW always gives.”

Participant 5: “The CHW enquires about my treatment – how do I take it and not to take treatment with alcohol. I am a traditional healer so the CHW would always preach to me about the importance of not mixing my treatment with traditional medicines. The CHW talks about condomising and that the spreading of HIV/AIDS is not only through sex.”

Participant 6: “We talk about HIV each time she visits. The CHW stresses the importance of condomising. We talk about my high blood pressure, diabetes and HIV treatment and to take my treatment regularly. We also do a pill count. The CHW inform me that HIV/AIDS is incurable but controllable.”

Participant 7: “The CHW and I talk about HIV/AIDS – what it is, how did we get HIV, how HIV is spread, safe sex, many sexual partners etc. Regular talking of

treatments is always emphasized by the CHW. Not to mix treatment with alcohol, to always eat before taking treatment and not to default treatments as this can be dangerous to our health."

Participant 8: "The CHW and I talk about HIV – what it is, how to prevent re-infection, condom usage, to encourage partner to be tested too. Talk about life styles – not to drink, not to have multiple social partners. Talking about treatment – to eat first before taking treatment and to continue taking treatment daily."

Participant 9: "The CHW encourages me to eat before taking my treatment and to take my treatment regularly and not to take treatment with traditional medicines. She also gives me pamphlets of what to eat and how to take care of myself at home for example to wash myself daily, comb my hair, to exercise and so on."

Participant 10: "The CHW gives me talks about my treatment – stressing the importance of taking treatment regularly. We do pill count. Talk about HIV/AIDS – how the number of people that have become infected have grown and what I think about that and how I think this can be prevented."

Table 4.5: Theme 5: Information and educational support received

Subthemes	**Number of**
Subthemes 4A: Health education	
Pill count	3
Taking of treatment correctly and regularly	10
Talking about HIV/AIDS	6
Practicing of safe sex	6
Prevention of re-infection	4
To eat before taking of treatment	3
HIV/AIDS cannot be completely healed	2
Follow-up dates at the clinic	4
Links between TB and HIV/AIDS	1
Not to take treatment with alcohol or traditional medicines	5
The danger of having multiple sexual partners	5

Mandle (2002:12) supports the importance of information and educational support as they help people to change their lifestyle and to move towards a state of optimal health.

The CHWs were informative; they gave education to participants and their family members whenever necessary. The CHWs focused on HIV/AIDS, treatment thereof and the prevention of the spread of the infection. In addition the CHWs also had care plans about information regarding personal hygiene, the care of minor ailments and basic needs of participants. Whenever there was a need for CHWs to give out this information, they did so. A summary of the themes regarding informational and educational support are captured in table 4.4.

4.8. SUMMARY

The process of data analysis as described by De Vos (2005:334) was followed. The aim and objectives set for the study were reached.

4.8.1. AIM

The aim of this study was to evaluate the effect of an informal caregiver's programme on the care of patients infected with HIV/AIDS. The aim was successfully investigated, showing a positive outcome of the informal caregiver's programme in the care given to HIV/AIDS infected patients. Though there is still a lack of spiritual care and some lack of educational support, the programme had a very positive effect on the care and lives of infected patients.

4.8.2. OBJECTIVES

The specific objectives set for the research to evaluate the specific care that patients received from caregivers physically, socially, spiritually, emotionally and the information and educational support given were successfully evaluated.

Hlophe (2008:185) in support of the findings of this research study (she completed research on CHWs and the response to HIV/AIDS in South Africa) concluded that

CHWs have become important players in the public health care sector in South Africa. Hlophe further said that it was clear that several generations of AIDS interventions would not have been possible without their participation. CHWs are generally seen to be adding value and meeting new needs, rather than simply substituting for professionals.

This study was further supported by Uys (2002:99-108) who compared communities in which CHWs were available to those communities in which CHWs were not available. The recommendation was that each community should have CHWs, as CHWs had proven themselves to be effective and efficient, but they need the support and advocacy of the health sector.

Added to this, Lehmann and Sanders (2007:vi) pointed out that CHWs are a good investment but that they are neither the “panacea” for weak health care systems nor a cheap option to provide access to health care for underserved populations.

Comparing Dr. Ivan Tom’s Clinics’ informal caregiver’s programme of basic human needs based on Maslow’s theory (see Annexure D, page 89) the basic human needs as formulated in the conceptual theoretical framework described in chapter 2, it was identified that the informal caregiver’s programme, as guided by the theorists, was effective in meeting the basic needs of the participants affected and infected with HIIV/AIDS.

Physically community health workers assisted in household chores, the preparation of meals and the giving of medication to treat opportunistic infections.

Socially community health workers helped participants deal with their social problems e.g. physical abuse, by making use of the resources available to them (e.g. police station).

Emotionally community health workers were sensitive, understanding, gentle and sympathetic and by doing so provided a conductive environment for participants – allowed participants to communicate their anxieties, fears and enable them to take better care of themselves.

Educationally / informationally community health workers gave advice whenever necessary and educated family members on how to take care of the participants.

4.9. CONCLUSION

In this chapter the data analysis, interpretation and simultaneous discussion of results were discussed. The aim and objectives set for this study were investigated successfully. In the following chapter the recommendations based on the findings of the research will be discussed.

CHAPTER 5

DISCUSSION, RECOMMENDATIONS AND CONCLUSION

5.1. INTRODUCTION

According to Clarke (2008:680), using CHWs in the community to provide health care is a practice with a long history in South Africa. The development and implementation of community health worker (CHW) programmes grew during the 1970s and 1980s, following the Alma-Ata Declaration and in response to the inadequate provision of primary health care under apartheid.

A CHW may be defined as 'any health worker delivering health care, trained in the context of the intervention, and having no formal professional, certificated or degree within tertiary education'. CHW project development and implementation in South Africa is well described (Dick, 2008:680-681).

5.2. INFORMAL CAREGIVER'S PROGRAMME

An informal caregiver's programme is any programme performed by CHWs at community level in advocating for and accessing health services, and assisting the community to become better informed about health priorities.

All HIV/AIDS participants interviewed for this study agreed that the informal caregiver's programme had a positive impact on their quality of life. One participant explained: "By joining this programme you are not alone. I am not afraid of HIV and have accepted that HIV is part of my life experiences." Another participant stated: "I have accepted my status and I live positively – after all life must go on." Implementation of more informal caregiver's programmes are recommended as people with HIV/AIDS and their families gain more information on how to take good care of people with HIV/AIDS.

Regular visitations from informal caregivers have proven to make a vast difference in the lives of people living with HIV/AIDS. Through this programme people living

with HIV/AIDS have gained friends, they could verbalize their feelings and fears, talk about their problems, they were cooked for and cleaned, domestic violence, abuse and excess alcohol consumption could be identified and then properly referred.

5.3. PHYSICAL CARE

Physically participants were well cared for by the CHWs, though nothing was said about family members taking care of their relatives' basic needs. At the same time nothing was said about CHWs teaching participants on how to take care of their own needs.

Recommendation

It is recommended that family members be given special training on how to take care of their HIV/AIDS affected relatives, for example 'how to handle soiled bedding and prevent contamination'. HIV infected patients are also to be taught how to look after their own health – if they are strong enough to do so – not just lie down, sit down or just watch television all day.

5.4. SOCIAL CARE

Participants are not as sick as before they started the treatment. CHWs helped participants to deal with their social problems by making use of the resources available to them.

Recommendation

It is therefore recommended that participants look for part-time jobs or do some volunteer work at the clinics and not depend solely on grants for a living. Participants need to keep themselves busy so that they do not have time for alcohol or drug abuse. They can do gardening, start a vegetable garden and sell it or do some sewing or knitting. The CHWs need to stress the fact more to the participants that they should not tolerate any form of abuse and to report the abuse to the police.

5.4.1. COMMUNITY PARTICIPATION

According to De Vos (2005:407), community participation leads to the creation of a democratic system and procedure, this enables community members to become actively involved and to take responsibility for their own development. In this way, all share equally in the fruits of community development and their decision making power is improved. It provides a sense of belonging or identity, a commitment to common norms, a willingness to take responsibility for oneself and others, and a readiness to share and interact. The end product is community empowerment, the process of increasing personal, interpersonal and political power, enabling individuals, single or collectively, to improve their life situation. Empowerment increases the energy, motivation, coping and problem-solving skills, decision-making power, self-esteem, self-sufficiency and self-determination of community members (Kirk, Glendenning and Glendenning, 1998:373).

Recommendation

More educational programmes and projects around HIV/AIDS are recommended. In this way the community becomes aware or will gain more knowledge about HIV/AIDS. The more knowledge the community has, the more the acceptance of HIV/AIDS infected persons there will be. The more the acceptance of HIV/AIDS infected persons, the lesser the isolation and loneliness, resulting in a more open, communicative, informative and care driven community.

5.5. SPIRITUAL CARE

The study has shown a large lack of spiritual support, no visitations were made by ministers at all to participants and their families. Only one participant indicated that her church has a HIV/AIDS programme.

Recommendation

Ministers need to be more actively involved in the fight against HIV/AIDS. Spiritual care practices should be encouraged in church e.g. prayer, church attendance, meditation and regular communication with the ministers. Spirituality provides a meaning and purpose in life. It is recommended that the churches should have

educational programmes around HIV/AIDS and support systems. Ministers should also get informal training as is the case with CHWs and making use of nurses available in their churches to teach congregants about HIV/AIDS. Government to start having HIV/AIDS policies to be implemented in churches too.

5.6. EMOTIONAL CARE

Care and support is needed to overcome the stigma associated with HIV/AIDS, to bolster self esteem, to gain a sense of control and to reduce loneliness. Formulation of support groups for HIV/AIDS infected people is the key solution. Support groups can accomplish this through comparison with peers, through enhanced situation-specific efficacy and through two-way exchange that reduces feelings of indebtedness and dependency (Friedman, 2002:161). This can be established by forming of support groups in the community through the help of nurses, doctors, community health workers and community members.

Support groups create provision of diverse types of support – informational, spiritual and emotional. The support groups enhance coping, communication and positive attitude; they also reduce feelings of isolation and entails talking with others who understand.

Support groups were one of the problem areas in this study. Despite the fact that there was a support group at the clinic, participants did not attend regularly and the support groups in the community were not functional.

Recommendation

5.6.1. SUPPORT GROUP

Participants and their families need to be part of a support group so as to unload their concerns or problems, to share their feelings with people who will understand them. To have informal caregivers who visit once or twice per week is not enough, because people living with HIV/AIDS need time and support to help them deal with their life experiences.

5.6.2. COUNSELLING

Regular visits to the clinic for counselling are highly recommended for people living with HIV/AIDS and their family members. Counselling ensures the exploration of feelings and the ventilation of fears. People living with HIV/AIDS need somebody who will just listen to them and not be judgemental.

5.7. INFORMATIONAL AND EDUCATIONAL SUPPORT

Information and education was given by the CHWs to the participants and their family members whenever necessary.

Recommendation

On the spot training of participants and their family members is recommended. The use of pamphlets given to them will be of an advantage if the participant can read. The continuous training of CHWs is also of great importance, through the regular attendance of in-service training regarding the latest update on HIV/AIDS. On-going in-service training should be based on needs assessments done by CHWs themselves in consultation with their community (facilitated by trainer).

5.8. CONCLUSION

The CHWs form a very strong support base for the participants. They form part of the health care team and ease the work load and pressure of the professional health workers. These workers are much needed, not only at the clinics but by the communities as well. They are accessible to patients at home through the home visits they perform. Community health workers fulfil the aim of the Alma-Ata (1978) Conference that stressed the importance of bringing health care to the poor.

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ANNEXURE A: INTERVIEW SCHEDULE

 UNIVERSITEIT·STELLENBOSCH·UNIVERSITY jou kennisvennoot • your knowledge partner	**Title** The effect of an informal caregiver's programme on the care of patients infected by HIV/AIDS

Leading questions

1. Tell me everything that the caregivers have done for you, pertaining to emotional, social, educational and spiritual support?

2. Do you consider the care given to you by the community health worker to be helpful? Why?

3. Give your understanding of what the informal caregiver's programme is all about.

4. What more can be done for you?

ANNEXURE B: ETHICAL APPROVAL

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot · your knowledge partner

14 December 2009 **MAILED**

Mrs N Zulu
Department of Nursing
2nd Floor,Teaching building
Stellenbosch University
Tygerberg campus
7505

Dear Mrs Zulu

"The effect of an informal caregivers programme on the care of HIV/AIDS affected patients."

ETHICS REFERENCE NO: N09/11/337

RE : APPROVED

It is a pleasure to inform you that a review panel of the Health Research Ethics Committee has approved the above-mentioned project on 14 December 2009, including the ethical aspects involved, for a period of one year from this date.

This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in ALL future correspondence. You may start with the project, but this approval will however be submitted at the next meeting of the Health Research Ethics Committee for ratification. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.

Please note a template of the progress report is obtainable on www.sun.ac.za/rds and should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Approval Date: 14 December 2009 Expiry Date: 14 December 2010

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

ANNEXURE C: INFORMED CONSENT

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY jou kennisvennoot • your knowledge partner	**Title** The effect of an informal caregiver's programme on the care of HIV/AIDS infected patients.

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Mrs. Nompumelelo Patience Zulu

ADDRESS: 29 Keurboom Street
Plattekloof
Parow
7500

CONTACT NUMBER: 082 766 4979

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Committee for Human Research at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The study will be conducted at Mfuleni Township in the Cape Metropolitan Area, with ten (10) participants or until saturation point is reached. The project aims at assessing how helpful the programme of community health workers is in caring for people infected with HIV/AIDS at home. The specific objectives are to evaluate ("measure") the specific care that patients received from the caregivers regarding to:

- Emotional support
- Social support
- Informational and educational support
- Spiritual support

You will be asked to read this information pamphlet and then voluntary consent to participate in the interview. An interview will be scheduled at a time convenient to you and will be approximately 30 minutes in duration. During this time I will ask you to share your experience regarding the support that you have received from the caregivers with me. The information will be tape recorded if you agree and / or written down on paper. All the information will be managed by the researcher, supervisor, and statistician only. The tapes and the written information will be stored in a locked cupboard and participants will be informed about the results.

Why have you been invited to participate?

You have been invited because you are one of the people that received care from the informal caregivers, and would be able to respond to the questionnaire.

What will your responsibilities be?

To allow me to interview you for about 30 minutes during which time I would appreciate you to give honest and best answers to the questions.

Will you benefit from taking part in this research?

There will be no money or direct benefits to you for participating in the study. The benefit is to help the researcher to determine whether informal caregivers contribute to the care of HIV/AIDS infected patients.

Are there in risks involved in your taking part in this research?

We do not anticipate any risks by participating in the study. Your involvement is voluntary and all information will be treated with confidentiality.

If you do not agree to take part, what alternatives do you have?

Participation is voluntary; refusing to take part will not influence your treatment.

Who will have access to your medical records?

Confidentiality will be ensured, all written information obtained will be managed by the researcher, supervisor and statistician only. All documents and tapes will be stored in a locked cupboard accessible to the researcher only and will be destroyed after a period of five years after the completion of the study.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study.

Is there anything else that you should know or do?

You can contact Dr. E.L. Stellenberg at tel. (021) 938-9036 if you have any further queries or encounter any problems during the interview. You can contact the Committee for Human Research at (021) 938-9207 if you have any concerns or complaints that have not been adequately addressed by the researcher during the interview. You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I …….. agree to take part in a research study entitled **'The effect of an informal caregiver's programme on the care of HIV/AIDS infected patients**.'

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…… on (*date*) ……..……..... 2010.

....

Signature of participant Signature of witness

Declaration by investigator

I *(name)* ……..……. declare that:

I explained the information in this document to ……..
I encouraged him/her to ask questions and took adequate time to answer them.
I am satisfied that he/she adequately understands all aspects of the research, as discussed above
I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…..…… on (*date*) ……..…….. 2010.

....

Signature of participant Signature of witness

ISIHLOKO SOPHANDO LOFUNDO

Igalelo kwinkqubo yabancedi abanga qeqeshwanga abakhathalele abantu abaphila nesifo sikagawulayo.

Reference Number:

Isifungo somthathinxaxheba:

Mna

……

Isazisi ……

A. Ndiyafunga ukuba:

1. Ndivumile ukuthatha inxaxheba kuphando olwenziwa yiyunivesithi yase Stellenbosch.
2. Ndifundile okanye ndifundelwe ngolulwazi nephepha – mvume kwaye libhalwe ngolwimi endiluvayo nendiluthethayo.

2.1 Ndilifumene ithuba lokubuza imibuza kwaye ndazifumana iimpendulo ngokufanelekileyo.

2.2 Ndiyaqonda ngokuyhathinxaxheba kolufundo kungokuzi - thandela kwaye khange ndinyanzeliswe ngokuthathi – nxaxheba.

2.3 Ndingayeka naninina ukuthatha inxaxheba kolufundo kwaye akukho nto indibambayo ukuba ndingayeki.

2.4 Ndingacelwa ukuyeka phambi kokuba ufundo luphele ukuba umphandi okanye ugqitha wolufundo ucinga ukuba ndifanelwe koko okanye andilandeli miqathango ekufanele ndiyilandele.

B. Ndiyavuma ukuthathinxaxheba ngokuzithandela koluphando.

Ityikitywe (*ndawo*) .....…..…… nge (*suku*) ……..…….. 2010.

....

Umthathinxaxheba Ingqina

Isifungo somphandi

Mna …… ndiyafunga ukuba mna:

1. Ndilucacisile olulwazi lukulamaphepha ku …….....
2. Ndimkhuthazile ngokubuza imibuzo kwaye ndimnike ixesha elaneleyo lokuphendula.
3. Ndanelisekile ukuba ucacelwe zizo zonke iinkalo zoluphando luxoxiweyo ngentla.
4. Incoko yethu ibingesi Xhosa kwaye khange ndisebenzise mcacisi.

Ityikitywe (*ndawo*) .....……. nge (*suku*) ……..……. 2010.

....

Umthathinxaxheba Ingqina

ANNEXURE D: DR. IVAN TOM'S CLINIC: INFORMAL CAREGIVER'S PROGRAMME OF HUMAN NEEDS

	ASSESSMENT	FREQUENCY	RE-ASSESSMENT
5. INFORMATIONAL & EDUCATIONAL CARE	**I) INFORMATION** – What do you understand about HIV/Aids? – How many pills do you take & how do you take the pills? – Do you have any problems with taking your medicine? – Are you experiencing any side effects from the medication? ☐ Diarrhoea/vomitting ☐ Nausea ☐ Fever ☐ Headaches ☐ Fever – If so, how do you deal with that? **II) DEVELOPMENT** – Emphasize "VUKUZENZELE" concept e.g. growing your own vegetable garden. – Community health worker to give information about the following referral systems: ☐ clinic of treatment ☐ food supplement ☐ disability grant ☐ clinic for adherence counselling ☐ support groups ☐ hospice ☐ psycho-social counselling ☐ minister	**WHENEVER NECESSARY**	**WHENEVER NECESSARY**
4. EMOTIONAL CARE	– To who have you disclosed? ☐ Partner, when? ☐ Family, when? ☐ Friends, when? – Does your partner know his/her status? Yes☐ No☐ (If yes, is he/she on treatment?) – Have you experienced stigma or signs of social unacceptability? ☐ Yes ☐ No If yes, explain how:	**WHENEVER NECESSARY**	**WHENEVER NECESSARY**
	– Are you married or not? ☐ Yes ☐ No – Does your partner live with you? ☐ Yes ☐ No – Are you or your partner on any form of contraception? ☐ Yes ☐ No – Did you use a condom the last time you had sex? ☐ Yes ☐ No – How often do you use a condom? ☐ Always ☐ Sometimes ☐ Never – How do you feel about your status? – Do you belong to any support group? ☐ Yes ☐ No – How often does the minister visit you?	**WHENEVER NECESSARY**	**WHENEVER NECESSARY**

<table>
<tr><td>3. SPIRITUAL CARE</td><td colspan="2">– Do you attend church? Yes☐ No☐
– Do you read the Bible? Yes☐ No☐
– How often do you pray? Always☐ Sometimes☐ Never☐
– Any spiritual support from: Congregants☐ Minister☐
– How often does the minister visit you?</td><td>WHENEVER NECESSARY</td><td>WHENEVER NECESSARY</td></tr>
<tr><td rowspan="2">2. SOCIAL CARE</td><td colspan="2">– Is your home? Your own☐ Rented☐ Shack☐ Shared, with whom?
– What distance are the following from your home?
☐Water:_____ ☐ Electricity:_____ ☐ Toilet:_____
– Do you own a fridge/freezer (specifically for storing medicine):
☐ Yes ☐ No
– Who lives with you at home & what is their relation to you?
– How supportive is your family?
– Do you feel safe at home?☐ Yes ☐ No Explain:
– Does any form of domestic violence affect this family such as wife beating or child abuse? ☐ Yes ☐ No
(If yes, is the violence reported to the police?)</td><td>AS NEEDED</td><td>AS NEEDED</td></tr>
<tr><td colspan="2">INCOME:
– Are you or anyone else in the household working or earning money? Yes☐ No☐
– What is the total income in the household?
– Do you smoke or drink alcohol? ☐ Yes ☐ No
– Do you use any form of drugs? ☐ Yes ☐ No
– Do you need help with alcohol or drug abuse? ☐ Yes ☐ No (If yes, refer)
– Do you get a disability/social grant? ☐ Yes ☐ No (If necessary, refer)
– How do you get food?</td><td>AS NEEDED</td><td>AS NEEDED</td></tr>
<tr><td rowspan="4">1. PHYSICAL CARE</td><td colspan="2">CARE PLAN:</td><td rowspan="2">EACH VISIT BY CARER/ DAILY BY FAMILY</td><td rowspan="2">WEEKLY</td></tr>
<tr><td>ASSESSMENT</td><td>CARE REQUIRED:</td></tr>
<tr><td>PERSONAL HYGIENE</td><td>Mouth care, nail care, foot care, bed bath, hair care
- wash hair bi-weekly, change linen</td></tr>
<tr><td>NUTRITION & CONSTIPATION</td><td>Health education/promotion, dietician if needed
Social services – no food, no appetite – small frequent meals.</td><td>DOCUMENT BOWEL ACTION EACH VISIT</td><td>WEEKLY</td></tr>
<tr><td>DEHYDRATION</td><td>Check for signs of dehydration, if patient is having loose stools advice to drink a glass of salt/sugar solution after each stool. Refer to clinic if patient’s condition gets worse</td><td>AS NEEDED</td><td>AS NEEDED</td></tr>
</table>

	PRESSURE CARE	– Health promotion/education to family. – Personal hygiene, rub bony areas with a water based cream. – Regular changing of position, linen smooth & lint free. – Passive and active exercise.	**4 HOURLY BY FAMILY, EACH VISIT BY CARER**	**WEEKLY**